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The Impact of a Blended Cognitive Remediation and Cognitive Behavioral Group Therapy for Pediatric Oncology Survivors: A Mixed Methods Approach

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The Impact of a Blended Cognitive Remediation and Cognitive Behavioral Group Therapy for Pediatric Oncology Survivors: A Mixed Methods Approach

by

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Dedication

This dissertation is dedicated to my husband, Kyle. Thank you for all your support and love over the last six years. I am so blessed to have you beside me on this journey.

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The Impact of a Blended Cognitive Remediation and Cognitive Behavioral Group Therapy for Pediatric Oncology Survivors: A Mixed Methods Approach

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Advances in cancer treatment have led to a significant increase in the number of pediatric oncology survivors. These survivors often have late effects in their cognitive, academic, executive, and psychological functioning subsequent to their chemotherapy and radiation treatment. In particular, executive functioning (EF), which is crucial for cognitive and academic functioning, has been recognized as an area that is impacted by treatment. Several studies have described cognitive remediation programs that seek to improve EF skills in pediatric oncology survivors. Although these programs have led to improvements in EF skills, they are often difficult to replicate due to the extensive time requirement. Many survivors also experience distress and anxiety and would likely benefit from cognitive behavioral therapy, which has been shown to be an effective intervention for children with internalizing disorders. Thus, a brief intervention that combines treatment for executive functioning and psychological distress is warranted.

A mixed methods study was conducted to evaluate the impact of a nine-week

blended cognitive remediation and cognitive behavior therapy group for pediatric oncology survivors and their parents. Participants were pediatric cancer survivors, age 9-14, and their parents who were referred through a local children's hospital that specialized in oncology treatment. Pre and post measures of EF, psychological functioning, and parental stress were examined. Semi-structured interviews with participants and their parents were completed and analyzed to learn more about the function of short-term group therapy for pediatric oncology survivors. Content analysis of the parent support group sessions was also conducted. Significant changes were found for youth internalizing symptoms, youth adaptive skills, youth executive functioning, and parental stress. There was also a positive correlation between parental stress and parent-rated youth internalizing problems as well as parent-rated youth behavioral symptoms and a negative correlation between parental stress and parent-rated youth adaptive behavior. Qualitative interviews indicated that participants felt that the intervention was helpful. Themes from the parent group included the challenge of managing late effects, balancing multiple roles, and coping with distress. Implications, limitations, and recommendations for further areas of research are presented.

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Chapter 1: Introduction

Approximately 11,630 children under the age of 15 will be diagnosed with cancer this year (American Cancer Society, 2013). Advances in cancer treatment have led to a significant increase in the number of pediatric oncology survivors (Duffey-Lind et al., 2006). As of 2008, more than 80% of pediatric oncology patients had reached five years of survivorship (Howlader et al., 2010). Children and adolescents can be diagnosed with a variety of different types of cancer, though the most common types are leukemia, specifically Acute Lymphotic Leukemia (ALL), and brain and central nervous system tumors (National Cancer Institute, 2008). While research has led to an increase in the number of survivors of ALL and brain tumors, the need for information about the late effects of various treatment options has also become more pressing.

Studies have shown that cranial radiation and intrathecal chemotherapy, which are commonly used in treating ALL and central nervous system tumors, have long-term effects on survivors' neurological, cognitive, and psychological functioning (for example, Butler & Mulhern, 2005). Children and adolescents who have received these treatments are often at risk for deficits in attention, memory, and processing speed as well as other areas encompassed within executive functioning (Butler & Copeland, 2002). These difficulties in executive functioning often impact cognitive and academic functioning (Raymond-Speden, Tripp, Lawrence, & Holdaway, 2000).

The psychological effects for survivors include elevated rates of distress, depression, anxiety, and post-traumatic stress disorder (Askins & Moore, 2008; Kazak et al., 2004). Similarly, the patient's family members often have elevated levels of distress

and are at increased risk for internalizing disorders due to the many uncertainties associated with cancer diagnosis and treatment (Bayat, Erdem, & Kuzucu, 2008). Thus, while the number of survivors has increased steadily over the last thirty years, so has the number of survivors and their families who are now coping with multiple late effects.

Various interventions have been developed to assist survivors with the neurological and cognitive late effects. Cognitive remediation appears to be the most promising of the interventions (Butler & Mulhern, 2005). Butler and his colleagues have developed a three-part program, which includes cognitive remediation, meta-cognitive techniques, and cognitive behavioral strategies (Butler et al., 2008). While the intervention has been effective in increasing the participants' knowledge of learning strategies and improving attention, as measured by parent report, the intervention may be difficult to replicate given the extensive time commitment. Other short-term cognitive remediation programs have been developed, but they do not include any psychological intervention (Kesler, Lacayo, & Jo, 2011; Luton, Reed-Knight, Loiselle, O'Toole, & Blount, 2011).

The psychological late effects experienced by youth and the related impact on family functioning has also received attention within the literature. A wide variety of support groups have been conducted to assist with the challenges of cancer diagnosis and treatment (Zabalegui, Sanchez, Sanchez, & Juando, 2005). The effectiveness of these groups has been quite variable, as qualitative measures tend to reflect feelings of support and encouragement, though limited evidence exists for improvement in psychological functioning, particularly for youth (Seitz, Besier, & Goldbeck, 2009). While support

groups have shown to lead to improvements in depression, anxiety, and quality of life for adults (Zabalegui et al., 2005), few studies have produced these results for children or adolescents.

Cognitive behavioral therapy has been shown to be an effective intervention to improve children and adolescents' psychological functioning (Kendall & Suveg, 2006; Stark et al., 2006). Studies have highlighted how CBT has been successful for pediatric patients and children and adolescents with brain tumors (Powers, Jones, & Jones, 2005; Poggi et al., 2009). When combined with family therapy techniques, group cognitive behavioral therapy has also shown to lead to improvements in children and parents' post-traumatic stress symptoms (Kazak et al., 2004). Therefore, cognitive behavioral therapy appears to be an effective method to improve psychological functioning in children.

At this time, no intervention has been developed to address the executive functioning deficits and psychological difficulties associated with cancer treatment in a time-sensitive manner. This study describes a nine-week combined cognitive remediation and cognitive behavioral therapy group for pediatric cancer survivors and their families. A mixed methods study is useful for understanding the impact of the group on participants' executive functioning and psychological development. Participants were referred through a social worker at a local children's hospital that specializes in oncology treatment and were 9-14 years old. Children who are not currently in school were excluded, so that information about academic functioning was gathered from teachers.

Pre and post measures of executive functioning, psychological functioning, and parental stress were examined. In addition, a thematic analysis of parent group sessions was completed in order to learn more about the themes present in a parent support group. More information about the function of short-term group therapy, specifically one centered on cognitive remediation skills in combination with cognitive behavior therapy, was captured through semi-structured interviews with participants and their parents. These interviews were transcribed and coded for themes relating to different aspects of intervention using a content analysis approach of qualitative analysis. It was hoped that this blended group therapy would be efficacious and lead to the development of a manualized approach to improve executive functioning and psychological functioning in pediatric oncology survivors.

Chapter 2: Literature Review

The following analysis will review the current status of pediatric cancer, including the overall incidence rates, the variety of types of childhood cancer, and treatment options, in order to set the context of the larger study. The impact of chemotherapy, radiation, and other treatment will also be examined, with particular focus on the cognitive, neuropsychological, and psychological late effects. A review of pre-existing interventions to address neurological, cognitive, and psychological deficits will also be discussed. Finally, the proposal for a new integrated cognitive remediation and cognitive behavioral therapy group will be presented, detailing the components of the group therapy for children and their parents.

Introduction

According to the American Cancer Society's 2013 report, approximately 11,620 children under the age of 15 will be diagnosed with cancer this year. While more than 80% of children will survive for five years or more, cancer remains the second leading cause of death in U.S. children under 15 years old. From 2004-2008, the incidence rate was approximately 15.4 in 100,000 (Howlander et al., 2011). Thus, childhood cancer continues to be of major medical concern due to the high incidence and mortality rates.

Childhood Cancer

Childhood cancer survival rates are greatly impacted by the type of cancer that is present. There are 12 different types of childhood cancer (National Cancer Institute, 2008), which are commonly grouped into 4 categories, based on differences in the origin of the malignancy, histology, and frequency at various ages (McGregor, Metzger,

Saunders, & Santana, 2007). Whereas adult cancer is often influenced by environmental factors, such as nicotine use or exposure to the sun, pediatric cancer is more commonly linked to genetic or acquired mutations (American Cancer Society, 2011).

The most common pediatric cancer types are leukemia, which are blood cell cancers, and cancers of the brain and central nervous system (National Cancer Institute, 2008). Together, they make up about half of all cases of pediatric cancer. Brain tumors, which include gliomas and medulloblastomas, are the most common solid tumors. Other solid tumors, including neuroblastomas, Wilms tumors, and sarcomas (such as osteoscarcoma and rhabdomyosarcoma), are less common (National Cancer Institute).

Leukemia

Leukemia is the most common childhood cancer and accounts for 30% of all cases (National Cancer Institute, 2008). The most prevalent type of leukemia is acute lymphoblastic leukemia (ALL), which represents nearly three-fourths of all leukemia cases (Butler & Haser, 2006). ALL is defined by the presence of cancerous lymphoid cells in the bone marrow, which travel throughout the body to various organs, including the central nervous system (Butler & Mulhern, 2005). Treatment for ALL typically includes combination chemotherapy as well as intrathecal chemotherapy (ITC), in which the medication is administered directly into the cerebrospinal fluid (Butler & Haser, 2006). In most cases, ITC has replaced cranial radiation therapy due to the negative impact of the latter treatment on neurocognitive functioning. Treatment can persist for 30-36 months and often consists of several cycles of different types of chemotherapy followed by a period of rest (American Cancer Society, 2011). The second type of

leukemia, acute myelogenous leukemia (AML), is a cancer of one of several different types of bone marrow cells including myeloblasts, monoblasts, erythroblasts, or megakaryoblasts (American Cancer Society). Treatment for AML is generally similar to ALL treatment, although the cycles of chemotherapy tend to be shorter and more intense, thus allowing for a shorter overall treatment duration.

Tumors of the Central Nervous System

Tumors in the central nervous system (CNS) are the second most common cancer and are the most common solid tumor found in children under fifteen years old (Butler & Mulhern, 2005; McGregor et al., 2007). Compared to other types of cancer, CNS tumors as a group are fairly heterogeneous, as they vary in type of tissue or cell, location, and size, all which impact treatment outcomes (Butler & Mulhern, 2005). The survival rate of CNS tumors tends to be lower than leukemia, given the sensitive nature of the brain. Resectioning is typically the first step of treatment with CNS tumors, although the location of the tumor can have a significant impact on the plausibility of surgery. In addition, chemotherapy and/or radiation may also be necessary depending on the location, size, and likelihood of metastasis of the tumor. The most common CNS tumor is medulloblastoma, which is a tumor that begins in the cerebellum (American Cancer Society, 2011). Glioma, which are tumors that arise from one of three types of glial cells, are also fairly common. Other types of CNS tumors include those that begin in different types of cells (e.g. Schwannomas) as well as other parts of the brain (e.g. pineoblastomas).

Lymphomas

Lymphomas are cancers that affect the lymph system and are typically broken down into two categories: Hodgkins and non-Hodgkins lymphomas (American Cancer Society, 2011). The difference is based on the presence or absence of Reed-Sternberg cells, which are irregular versions of lymphocytes. Both types of lymphomas are generally treated with a combination of chemotherapy and/or radiation, depending on the location and severity of the tumor, as well as the age of the patient. Lymphomas represent the third most common pediatric cancer, after leukemia and CNS tumors (National Cancer Institute, 2011).

Other types

Other types of pediatric cancer include various solid tumors that are not located in the central nervous system, which include neuroblastoma (a disorder of the nerves that typically occurs in infants and very young children), Wilms tumor (which begins in the kidneys), rhabdomyosarcoma (cancer of the rhabdomoblasts, which are cells that form into skeletal muscles), and retinoblastoma (cancer of the eye) (American Cancer Society, 2011). In addition, two types of bone cancer, osteosarcoma and the Ewing Sarcoma family of tumors (which typically includes several types of cancer that begin in the bones or surrounding soft tissue), also occur in pediatric patients (American Cancer Society; McGregor et al., 2007). Like many other pediatric cancers, the typical treatment for these solid tumors includes a combination of surgery, chemotherapy, and radiation (American Cancer Society). Treatment is influenced by type of cancer, histology, severity, and age of patient (McGregor et al.).

Incidence and Survival Rates

Fifty years ago, survivor rates for pediatric oncology patients were very low: in fact, less than 25% of children survived in the 1960s (McGregor et al., 2007). Childhood cancer survival rates began to shift in the 1970s with the development of new protocols for pediatric cancer as well as increases in technology that allowed for better diagnosis. At the same time, incidence rates for pediatric cancer have increased slightly since the 1970s, which researchers attribute to improvements in medical technology that have led to earlier and more accurate diagnoses (National Cancer Institute, 2008). For children and adolescents ages 0-19, incidence rates between 1975-1983 were 142 cases per 1,000,000. Between 2001-2008, the incidence has increased to 166 cases per 1,000,000 (Howlander et al.).

While most childhood cancer survival rates have steadily increased over time, marked increases in the number of survivors of ALL and CNS tumors began in the 1970s with changes in treatment, which included "effective CNS prophylaxis" (Winick, 2011, p.29). These changes led to a decrease in the number of patients with CNS relapses, which previously often led to patient death (Butler & Haser, 2006). This prophylactic treatment was initially done with cranial radiation, but intrathecal chemotherapy is now more commonly used due to the neurocognitive effects associated with cranial radiation, which will be discussed in more detail in the following section. Cranial radiation continues to be used rarely, most commonly in high-risk patients or those who have experienced a CNS reoccurrence.

The term survivor is used frequently in the oncology literature, but it can be confusing as it has multiple definitions depending on the source of the information. For example, the American Cancer Society describes how "survivor" can be used to describe someone who has been diagnosed with cancer, someone who has completed cancer treatment, or someone is several years post-treatment (2013). Since it appears that the term "survivor", when used in the research literature, most commonly refers to patients who have completed treatment, this is the definition that will be used throughout this document.

The Impact of Treatment

As the number of pediatric cancer survivors increases, more research has been conducted to determine the impact of various treatment procedures, including chemotherapy, radiation, and surgery. The immediate side effects of treatment are generally well-known and may include nausea and vomiting, fatigue, poor appetite, mouth sores, hair loss, swelling, pain, constipation, or diarrhea, depending on the type of treatment conducted (American Cancer Society, 2011). However, the long-term impact of these treatments is a relatively new area of research, which has been studied in more detail over the last thirty years (Butler & Haser, 2006). At this time, it continues to be a popular area of research within pediatric oncology.

Physical Late Effects

The long-term impact of childhood cancer treatment, also known as the "late effects," has implications for physical, cognitive, neurological, and psychological development. Adult survivors of childhood cancer have increased rates for chronic

health problems, including "cardiovascular disease, renal dysfunction, severe musculoskeletal problems, and endocrinopathies (e.g., premature gonadal failure, thyroid disease, osteoporosis, and hypothalamic and pituitary dysfunction)" when compared to siblings who did not undergo oncology treatment (Oeffinger et al., 2006, p.1580). In their study of more than 10,000 adult survivors of childhood cancer, Oeffinger and colleagues found that survivors were eight times more likely than their siblings to develop a chronic health condition. In addition, the risk for second cancers has been determined to be approximately 2-3% for adult survivors based on a sample of nearly 1,000 childhood cancer survivors (Haddy, Mosher, Dinndorf, & Reaman, 2004). Other physical implications include auditory difficulties (e.g. hearing loss, problems hearing sounds, and tinnitus) (Whelan et. al., 2011); dental problems (e.g. an elevated rate of decayed, missing, or filled teeth than matched age peers) (Cubukcu & Sevinir, 2008), and difficulties with psychosexual functioning (van Dijk et al., 2008).

Cognitive and Neurological Late Effects

While numerous studies have indicated the presence of cognitive and neurological late effects for many types of cancer (e.g. Winick, 2011), the majority of research has focused on ALL and CNS tumors, as the treatment for these types of cancers typically involves chemotherapy or radiation to the central nervous system (e.g. cranial radiation therapy or intrathecal chemotherapy) (Butler & Mulhern, 2005). Debate exists within the literature about when these neurocognitive late effects begin, with some studies suggesting effects may be present 1-2 years post radiation (Bhatia & Constine, 2009),

whereas others suggest that it may 2-3 after treatment or 4-5 years from the beginning of treatment (Bisen-Hersh, Hineline, & Walker, 2011; Costa, 2010).

Cranial radiation therapy has been linked to difficulties in working memory (Butler & Mulhern, 2005) as well as deficits in "attention/concentration, intelligence, motor abilities and academic skills" (Butler & Copeland, 2002, p.116). Specifically, difficulties with attention are common, including maintaining and shifting attention and an increased vulnerability to distraction (Butler & Mulhern, 2005).

A meta-analysis of 28 studies of ALL survivors with and without cranial radiation indicated that survivors whose treatment included chemotherapy and cranial radiation performed worse on measures of overall cognitive functioning than survivors whose treatment only included chemotherapy (Campbell et al., 2007). However, the same study found that all survivors, regardless of radiation status, experienced executive functioning weaknesses. These results were consistent with the findings in another study that compared childhood survivors of ALL who were treated with chemotherapy to those treated with chemotherapy and radiation (Raymond-Speden, Tripp, Lawrence, & Holdaway, 2000). In order to gather information about the impact of chronic illness, children and adolescents who had been diagnosed with asthma were also included as a control group. The results indicated that the two ALL groups differed significantly from the asthma and control groups in intellectual and academic functioning. However, there were not statistically significant differences between the two ALL groups.

These studies indicate that survivors who received both chemotherapy and cranial radiation may experience the greatest neurological late effects, although those who

simply had intrathecal chemotherapy may also experience similar delays, including problems in attention, concentration, memory, and visual processing (Winick, 2011). However, these results have not been replicated consistently as numerous studies have found that survivors of ALL who were treated only with chemotherapy did not have significant cognitive deficits (Stam et al., 2001; Zebrack et al., 2002). As such, while it is challenging to determine the neurological impact of intrathecal chemotherapy, it appears that executive functioning deficits are common. Moleski described the situation well when she stated, "unfortunately, CNS-directed chemotherapy without CRT cannot be assumed to be a benign form of treatment" (2000, p.604).

Regardless of whether survivors were treated with cranial radiation, intrathecal chemotherapy, or a combination of both, the resulting weaknesses in neurological functioning have a significant impact on cognitive ability and academic functioning (Winick, 2011). While patients treated only with chemotherapy tend to have less severe neurological effects, negative impacts on academic and cognitive performance still persist. A 2006 study, which compared survivors of ALL and survivors of a Wilms tumor to siblings and a control group of healthy children, found that the ALL survivors who had received only chemotherapy had significantly lower scores on school performance, specifically for math and language skills, compared to the other three groups (Buizer, Sonneville, van den Heuvel-Eibrink, & Veerman).

While type of treatment certainly has an impact on severity of neurological deficits, there are several other factors that also play a role. First, patients who received more intense treatments are more likely to experience significant deficits than those who

had less intensive treatments (Butler & Haser, 2006). The patient's age at the onset of treatment also has a significant impact on late effects. In a 1999 study of 56 survivors of childhood leukemia, those whose treatment included chemotherapy and cranial radiation before the age of 54 months had significantly more difficulty with attention tasks compared to those who had the combined treatment later in their childhood (Lockwood, Bell, & Colegrove, 1999). Thus, it appears that the younger the child is during treatment, the larger the neurological impact will be. Gender also appears to influence late effects, as studies have shown that females tend to have a higher level of vulnerability to severe deficits (Butler & Mulhern, 2005).

Given the significant impact of cranial radiation and intrathecal chemotherapy on neurological and cognitive functioning, studies have examined the brain to determine how the deficits are produced. It appears that injury to the cortical and subcortical white matter, specifically to myelinated axons, is responsible for the majority of the delays in attention and memory (Butler & Haser, 2006; Winick, 2011). As radiation dosage increases, the white matter volume tends to decrease, which is consistent with studies in which patients with more intense treatments experienced more global late effects (Butler & Haser, 2006). Deficits in processing speed appear to be linked to limited communication between brain regions due to damaged white matter (Winick, 2011). Not surprisingly, there is also a relationship between white matter volume loss and losses in IQ (Butler & Haser, 2006). It can be concluded that cranial radiation and intrathecal chemotherapy have a direct impact on white matter, which then impacts various neurological functioning.

Psychological Late Effects

In addition to neurological and cognitive late effects, cancer diagnosis and treatment often has an impact on a survivor's psychological functioning. Studies have shown that survivors often have elevated levels of distress (Ljungman et al., 2003) and may be at higher risk for depression, anxiety, and post-traumatic stress disorder, compared to siblings or a control group (Askins & Moore, 2008; Kamibeppu et al., 2010; Li, Chung, & Chiu, 2010). A large-scale study of nearly 7000 young adult survivors of pediatric cancer and their siblings, from the Childhood Cancer Survivor Study, indicated that survivors are 1.5 times more likely than siblings to experience symptoms of depression and somatic complaints (Zebrack et al., 2002). In a study of 28 child and adolescent survivors of ALL who received only chemotherapy, parents rated survivors higher on several measures on the Child Behavior Checklist, including withdrawal, anxious/depressed, and social problems (Buizer, Sonneville, van den Heuvel-Eibrink, & Veerman, 2006).

A study of 182 young adult survivors of pediatric cancer found that 15% of survivors met criteria for post-traumatic stress disorder (PTSD) since the time of their treatment, with the majority of them continuing to meet criteria at the time of the study (Rourke, Hobbie, Schwartz, Kazak, 2007). Females had higher rates of PTSD than males, which is consistent with the overall literature for psychological late effects (Kamibeppu et al., 2010). Kazak et al. (2004) noted that PTSD symptoms tend to elevate over time, such that young adult survivors are at greater risk for PTSD or post-traumatic stress symptoms than child or adolescent survivor groups. It appears that symptoms may

intensify over time, which is consistent with other studies that indicated a higher risk for psychosocial problems after treatment ends (Ljungman et al., 2003). Minority ethnic status and low social economic status appear to have an impact on intensity of psychological deficits as well (Cantrell, 2007). Other factors that influence the presence of psychological late effects include the intensity of cancer treatment, use of cranial radiation, and early age at diagnosis (Stam, Grootenhuis, & Last, 2001).

Survivors may also experience psychosocial deficits and decreased opportunity to interact with peers. While certain types of treatment, including cranial radiation, have been linked to social difficulties (Butler & Mulhern, 2005), it appears that the changes in psychosocial functioning may be a function of limited time that children with cancer have to spend with their friends or classmates. Cancer diagnosis and treatment provides particular challenges for older children and adolescents in this respect, as many youth are attempting to become more independent and autonomous at this stage in their life (Cassano, Nagel, & O'Mara, 2008). For youth with cancer, their medical needs often lead to an increased reliance on their parents and few opportunities for independence. At the same time, when children complete treatment and begin to reintegrate back into their schools, it may be challenging for them to relate to their peers, who have not experienced cancer or other life-threatening illnesses. As a result, it can be difficult for survivors to connect with their peers and feel understood by others, which may lead to feelings of isolation, loneliness, and even depression (Askins & Moore, 2008).

While much of the literature highlights the negative psychosocial implications of cancer diagnosis and treatment, several studies have emphasized the positive

consequences of cancer for youth. For example, in a qualitative study of 38 Swedish adolescents and young adults (ages 15-21) completed two years after diagnosis, Mattsson, Ringne, Ljungman, and von Essen (2007) found that all but two of the participants noted positive implications of cancer, including an increase in maturity, self-esteem, and empathy for others. Similarly, in a study of Latino adolescents and young adults, positive themes of gratitude, empathy, increased faith and spirituality, and a shift in priorities were found (Jones et al., 2010). These feelings of gratitude and empathy are consistent with the idea of post-traumatic growth, in which individuals who have experienced a significant, and potentially traumatic life event, are able to find some positive interpretation of the event and see it as having a positive impact on their lives (Zebrack et al., 2012). Thus, it is important to be aware that youth may have a wide range of psychological responses following their cancer treatment.

Impact of Cancer on Families

While cancer diagnosis and treatment has a significant impact on the patient receiving treatment, the patient's family often experiences a great deal of psychological distress as well. In addition to the significant worry associated with the child's well-being and concerns about treatment and relapse, parents are often required to increase their care for their children, which can lead to feelings of isolation and loneliness as well as potential job loss and economic stress (Bayat, Erdem, & Kuzucu, 2008). In their study of child and adolescent survivors and their parents, Kazak et al. (2004) noted that nearly 30% of mothers of cancer survivors indicated that they met criteria for PTSD at some time since their child's diagnosis. Feelings of hopelessness, worry, and depression are

common in parents, particularly mothers, and are generally negatively related to perceived social support (Bayat et al., 2008).

Multiple studies have indicated that child and adolescent functioning and adjustment is related to parent support, parent level of distress, and overall family functioning (Ljungman et al., 2003; Robinson, Gerhardt, Vannatta, & Noll, 2007). In their 2010 article, Ozono et al. found that families that were characterized by high levels of conflict and low levels of cohesion and expressiveness had higher rates of depression, anxiety, and PTSD than families with generally positive or average family functioning.

Similar to the impact on children and adolescents, families typically experience notable negative consequences of their children's treatment. However, several studies have found positive implications for family functioning following cancer diagnosis and treatment. Berger and Weiss (2009) applied the post-traumatic growth model to families and described how they can be transformed after exposure to a traumatic event, such as a child's cancer diagnosis and associated treatment. Similarly, in their qualitative study of bereaved families of children with cancer, Rosenberg, Baker, Syrjala, Back, and Wolfe found that several families described the benefit or meaning that they experienced after the loss of their children (2013). Taken together, families can have a variety of reactions to their children's cancer diagnosis and treatment and it is important to consider both positive and negative outcomes.

Interventions for Neurological and Cognitive Late Effects

Based on the extensive neurocognitive late effects that pediatric cancer survivors experience, research has explored various interventions that may assist survivors with

these deficit areas. Much of this research has been taken from successful interventions with childhood traumatic brain injury survivors, since the neurological and psychological deficits tend to be similar (Butler & Mulhern, 2005).

One intervention is pharmacotherapy, specifically stimulant medication, such as methylphenidate hydrochloride (MPH), which is commonly used for children and adolescents with attention deficit hyperactivity disorder (ADHD) (Butler & Mulhern, 2005). Since child and adolescent cancer survivors often have attention problems similar to ADHD, researchers have considered the use of MPH with the pediatric cancer survivor population. While some evidence has indicated that the use of MPH can be helpful in tests of sustained attention, there has been little impact on academic achievement, another area in which survivors often have difficulty.

Another primary intervention that has been reviewed in the literature is cognitive remediation (CR), which is a broad category of techniques designed to improve cognitive functioning. CR typically involves repeated practice of specific skills, such as techniques to sustain attention or improve cognitive flexibility (Butler & Mulhern; Tchanturia, Davies, & Campbell, 2007). CR was developed at the end of the 19th century and increased in popularity following World War I when many soldiers returned to the US with traumatic brain injuries (Parente, 2008). CR has been used with a variety of disorders and neurological conditions including schizophrenia, anorexia nervousa, traumatic brain injury, stroke, and attention deficit hyperactivity disorder (McGurk, Twamley, Sitzer, McHugo, & Mueser, 2007; O'Connell1, Bellgrove, Dockree, & Robertson, 2006; Pyun et al., 2009; Tchanturia et al., 2007).

Research on the use of CR with TBI and stroke in adults is extensive and has been shown to be efficacious. However, few studies detail specific treatment and patient factors (Flanagan, Cantor, & Ashman, 2008). Similarly, the literature basis for CR with pediatric patients tends to highlight the use with children with various traumatic brain injuries, typically in a case study or small group format, given the heterogeneity present within TBI (Crowley & Miles, 1991; Suzman, Morris, Morris, & Milan, 1997). Treatment tends to focus on problem solving, goal setting, and other cognitive strategies, provided in a small group or computer-based format. However, the frequency and duration of the training appears to be quite varied, which makes it challenging to define the minimum amount of training that would lead to positive behavior change. Despite the challenge of not having a well-defined intervention, several programs using cognitive remediation have been developed to address late effects in pediatric oncology survivors.

Cognitive Remediation for Cancer Survivors

Robert Butler and his colleagues have developed a three-part cognitive remediation intervention designed for child, adolescent, and young adult survivors of pediatric cancer (Butler et al., 2008). Their program has been influenced by three domains: "brain injury rehabilitation, special education and educational psychology, and clinical psychology" (Butler & Copeland, 2002, p.117). The first component is attention process training, in which patients complete learning tasks geared to increase their sustained, selective, and divided attention, over twenty two-hour sessions. Second, the patients learn various metacognitive strategies to increase their executive functioning skills, which target task preparation, on-task behavior, and post-task behavior (Spencer,

2006). As these skills are taught individually to the youth, parents and teachers are encouraged to remind them to use these skills throughout their day. For example, one skill would be to teach a child to check their work as part of the post-task skills; parents and teachers would then provide reminders for the child to check their work. Finally, the third component includes cognitive behavioral strategies such as monitoring self-talk, the use of reframes, and coping with weaknesses (Butler & Haser, 2006). An individual therapist, who adapts the program for the individual child, teaches the latter two skills. Typically the intervention includes 50 hours of treatment over a six-month period.

In 2008, Butler et al. published a "phase 3 randomized controlled clinical trial" which evaluated their cognitive remediation program and included 161 child and adolescent survivors (108 in the intervention group and 53 in the control group) at seven sites across the United States. The program led to a significant change in several areas of academic functioning (as measured by three language and four math scales), increased knowledge of learning strategies, and parent reported measures (e.g. cognitive problems, improved attention, and fewer ADHD symptoms). However, there were not significant differences found in the measures of brief focused attention, working memory, memory recall, or patient's self-esteem. While the intervention led to notable improvement in the patient's academic functioning, the time commitment of the intervention is extensive, which may be difficult to replicate given the challenge of finding participants that can commit to the entire program over a six month period of time. The authors also noted that they would like to increase the intervention with parents and teachers.

A modified version of Butler and colleagues' CRT program was done in 2011, which included 6 one-hour individual cognitive remediation sessions over a three-week period with 18 children ranging in age from 6-15 with various neurological impairments (Luton, Reed-Knight, Loiselle, O'Toole, & Blount). The intervention included teaching each participant 3-4 strategies per session and then communicating with parents about these strategies in order for them to encourage the child to practice them outside of the session. Pre and post measures included a widely used attention measure (TEA-Ch: Tests of Everyday Attention for Children) and parent-based questionnaires about attention and executive functioning. Significant differences were found on tasks measuring selective, alternating, and divided attention as well as one of the parent-report measures. While somewhat effective in improving attention, this program did not address the psychological late effects associated with treatment.

Another program that appears to be promising uses a computer-based cognitive remediation program known as Lumosity, which includes tasks focused on cognitive flexibility, attention, and working memory (Kesler, Lacayo, & Jo, 2011). In their pilot study, which included 23 pediatric cancer survivors ages 7-19, participants completed approximately 40 sessions over eight weeks at home. Results indicated that improvements were found in processing speed, cognitive flexibility, and visual and verbal declarative memory. Similar to the previous study, this program appeared to have initial improvements, however it did not address any of the psychological late effects of treatment.

In summary, few interventions have been developed to remediate the neurological and cognitive deficits associated with cancer treatment. Cognitive remediation appears to be the most promising intervention, although long-term impact of the intervention has not been evaluated. At this point, cognitive remediation appears to be effective in reducing neurological and cognitive deficits, but more studies need to be conducted in order to more fully understand the impact of CR on late effects.

Interventions for Psychological Late Effects

Given the distress associated with cancer diagnosis, treatment, and follow-up, several types of interventions have been described in the literature to assist survivors and their families with psychological late effects. Most interventions are conducted in a group format and involve either informal support or a more structured psychosocial intervention.

Support Groups

Support groups are defined as a "structured group composed of a few members who offer mutual support through interpersonal interactions" (Zabalegui, Sanchez, Sanchez, & Juando, 2005, p.370). Johnson and Lane (1993) defined four objectives for cancer support groups: (1) they encourage members to express their thoughts and feelings about living with the cancer and the associated risks, (2) they facilitate mutual support among members who are dealing with similar situations, (3) they provide accurate information about the illness and related treatment options, and (4) they help members find ways to further develop their coping and problem solving skills. In their meta-analysis of adult support groups for cancer patients and survivors, Zabalegui et al. found

that participation in a support group generally led to improvements in depression, anxiety, and quality of life (2005).

Support groups for youth survivors have been linked to feeling understood, as participants described that they enjoyed spending time with peers "who just know" (Cassano, Nagel, & O'Mara, 2008, p.195). The youth in this study also described how they felt a high level of comfort around the other cancer survivors and were able to discuss any topic that came up, compared to experiences with youth who have not had cancer. These results are consistent with several other studies that interviewed youth and their families about the type of support that they hoped to receive during or after treatment (Duffey-Lind et al., 2006; Ljungman et al., 2003). In both studies, youth indicated that they preferred a face-to-face support group with other patients or survivors as a means of receiving social support.

While youth often indicate qualitatively that support groups are helpful, a recent meta-analysis indicated that there are few evidence-based support groups available that have a significant impact on psychological functioning (Seitz, Besier, & Goldbeck, 2009). Another meta-analysis, which included 12 studies of child, adolescent, and parent psychological interventions, found significant effect sizes only for two parent measures (parent distress and parent adjustment) across the 12 studies (Pai, Drotar, Zebracki, Moore, & Youngstrom, 2006). Due to the variety of interventions included in the meta-analysis, it is difficult to define specific components that led to changes in parent functioning. However, it appears that a structured therapy group may provide more substantial benefits to youth.

Support groups have also been found to be helpful for parents of pediatric cancer patients or survivors. In their 2005 study of a six-week hospital-based support group for parents of pediatric oncology patients, Foreman, Willis, and Goodenough reported that parents noted overall positive satisfaction and described participating in the support group in order to gain information and meet other parents. Themes present in this intervention included coping skills, need for advocacy, and the parenting role. Similarly, a 2008 study of a computer-mediated support group for parents of pediatric cancer survivors over four months found that the intervention led to improvements in parental anxiety, depression, and stress (Bragadottir). Thus, support groups provide an opportunity for parents to connect with others who have had similar experiences and can lead to improvements in psychosocial functioning.

Cognitive Behavioral Therapy

Cognitive therapy, which was developed by Aaron Beck in the 1960s, is a theoretical orientation that views psychological problems as a result of maladaptive thinking which affects the individual's mood and behavior (Beck, 1995). Therapy is directed toward changing the individual's thoughts, feelings, and behaviors through affective education, coping skills, problem solving skills, and cognitive restructuring. CBT has demonstrated effectiveness with depression, anxiety, and other disorders, and has also proved effective with a pediatric population (Kendall & Suveg, 2006; Powers, Jones, & Jones, 2005; Stark et al., 2006). Thus, it may offer some promise for children who have survived cancer.

In a study of 40 child and adolescent survivors of pediatric brain tumors who were having behavioral and social problems, those who received CBT (which included coping skills, cognitive restructuring, exposures, and other behavioral techniques) had significant improvements over the control group (Poggi et al., 2009). These included changes in parent-reported measures of psychological functioning, including withdrawal, somatic complaints, social problems, attention problems, and internalizing problems. Improvements were also noted on the social skill section of an adaptive measure completed by parents.

Cognitive-behavioral therapy can also be useful for family interventions. Kazak and colleagues have developed the Surviving Cancer Competently Intervention Program, a family-based intervention that combines CBT with family therapy for child and adolescent survivors, their parents, and siblings who are experiencing post-traumatic stress symptoms (Kazak et al., 2004). This program, which includes four interventions held on one day, is a combination of groups held with survivors, mother, fathers, and siblings individually, multiple-family groups, and individual family meetings. Topics include discussion of experiences with cancer, reviewing and learning new coping strategies, and planning for the future of the family. Results from the program have generally been positive, with decreases reported in post-traumatic symptoms for youth and fathers, though decreases were not significant for mothers (Kazak et al., 2004; Kazak et al., 1999). The authors stated that they suspected that the most resilient mothers stayed in the group, while the mothers who were most distressed appeared more likely to drop out (Kazak et al., 2004). Thus, plans to reach more distressed families, specifically

mothers, were discussed. Few other interventions that use CBT specifically for survivors and their families were present in the literature.

The majority of psychological interventions for youth cancer survivors have been in a support group setting, yet the effectiveness of these groups has been mixed. Qualitative studies highlight the positive aspects of the group, including the benefits the participants receive from interacting with peers who have experienced similar circumstances. However, few quantitative studies have found corresponding changes in youth psychological functioning. Support groups for adult survivors and parents appear to have stronger implications, particularly regarding distress. Cognitive behavioral therapy has found to be effective for children and adolescents, yet few studies exist that highlight the benefits of CBT with pediatric oncology patients. It appears that the use of CBT within a supportive group environment would likely result in positive outcomes for pediatric cancer survivors, particularly when accompanied by a parent support group.

Summary

Given the joint deficits in executive functioning and psychological functioning that youth survivors of pediatric cancer experience, a combined cognitive behavioral therapy and cognitive remediation intervention appeared to be appropriate for this population. Based on the literature highlighting the importance of family functioning, a parent component was included in the intervention to provide parents with an opportunity to discuss their experiences of having a child with cancer. In order for the strategies presented in the group to be generalized at home and school, parents were informed about

the strategies within the support group. Teachers were also contacted in order for them to assist the youth in using the strategies in their academic environments.

Statement of the Problem

Over the last fifty years, significant advances have been made in pediatric oncology treatment, which have led to nearly 80% of patients reaching five years of survivorship (Howlader et al., 2010). As more children and adolescents survive, there has been an increased interest in the impact of chemotherapy and radiation treatment (for example, Meadows, 2006). Numerous studies have documented the late effects of these treatments, including changes in neurological, cognitive, academic, and psychological functioning (Butler & Haser, 2006; Jones et al., 2010; Winick, 2011).

Executive functioning, which includes working memory, attention, organization, cognitive flexibility, and inhibition, has received attention in recent years as an area that is significantly impacted by oncology treatment (Butler & Haser, 2006; Butler & Mulhern, 2005; Caron et al., 2009). Given the importance of these skills in academic and psychological functioning, several studies have described cognitive remediation programs that seek to improve the executive functioning skills in pediatric oncology survivors (Butler et al., 2008; Butler & Mulhern, 2005; Spencer, 2006). Although these programs have led to improvements in attention and academic functioning, they either did not address the psychological problems that are often concurrent with executive functioning weaknesses or were too lengthy to be frequently replicated. Cognitive behavioral therapy (CBT) has been shown to be an effective intervention for children with depression, anxiety, and other internalizing disorders (Kendall & Suveg, 2006; Stark

et al., 2006). Given that many survivors experience distress and elevated levels of anxiety (Askins & Moore, 2008), it is crucial to address the psychosocial needs of the survivorship population. At this time, no program has been developed that would target both executive functioning skills and psychological functioning, within a short-term intervention.

Statement of Purpose

The purpose of this concurrent mixed methods study was to better understand the impact that a combined cognitive remediation and cognitive behavioral group therapy had on pediatric oncology survivors and their parents. Measures of psychological and executive functioning were examined in combination with a semi-structured post-intervention interview with group participants. In addition, a thematic analysis of parent group sessions was completed in order to learn more about the themes present in a parent support group. Finally, the quantitative and qualitative data were compared to determine if the results across the two sets of data are consistent.

Research Questions, Hypotheses, and Rationale

Research Question 1: What was the pre-intervention level of psychological functioning of the participating youth? What impact did the combined CRT/CBT group have on the participants' psychological functioning?

Hypothesis 1a: It was hypothesized that the psychological functioning of the participating youth, as measured by the BASC-2 self and parent reports, would be above the mean for the clinical scales and below the mean for the adaptive scales in the pre-intervention assessment data. Individual pre-intervention BASC-2 scores were compared

to the 90% confidence interval of the general normative sample, based on participants' gender and age. In addition, descriptive statistics were used to determine if the pre-intervention scores were in the "at risk" range (T score of 60-69 for clinical scales and 31-40 for adaptive scales) or "clinically significant" range (T score of 70 or greater for clinical scales and 30 or below for adaptive scales).

Rationale: Pediatric oncology survivors often have elevated levels of distress (Ljungman et al., 2003) and may be at higher risk for various internalizing disorders (e.g. depression, anxiety, and post-traumatic stress disorder) than their siblings or matched age peers (Askins & Moore, 2008; Kamibeppu et al., 2010; Li, Chung, & Chiu, 2010). They may also be at elevated risk for social problems and social isolation due to the limited interactions that they have with peers and few opportunities for independence during their treatment (Buizer, et al., 2006).

Hypothesis 1b: Following the group intervention, the psychological functioning of the participating youth would have improved. Specifically, it was expected that the parent and youth report of youth psychological functioning as measured by the BASC-2 would be significantly lower for the clinical scales and higher for the adaptive scales. Repeated measures t-tests were used to compare pre- and post-intervention BASC-2 scores gathered from the self and parent reports to determine if the differences were statistically significant.

Rationale: Group therapy with similar peers has shown to improve youth's sense of belonging and connection to others, which is linked to decreasing feelings of isolation (Cassano et al., 2008). Cognitive behavioral therapy, specifically, has been shown to be

an effective intervention for various internalizing disorders (Kendall & Suveg, 2006; Stark et al., 2006) as well as for pediatric patients (Powers et al., 2005). Thus, it was expected that the combination of cognitive-behavioral group therapy provided within a supportive environment would lead to decreases in psychological difficulties and improvements in adaptive functioning.

Research Question 2: What was the pre-intervention level of executive functioning of the participants? What impact did the combined CRT/CBT group have on the participants' executive functioning?

Hypothesis 2a: It was hypothesized that the participating youth would have deficits in their executive functioning in the pre-intervention assessment, as measured by scores above the mean for self, parent, and teacher reports on the BRIEF. Individual pre-intervention BRIEF scores were compared to the 90% confidence interval of the general normative sample, based on participants' gender and age. In addition, descriptive statistics were used to determine if the pre-intervention scores were in the "clinically significant" range, as noted by a T score of 65 or higher.

Rationale: Many studies have shown that child and adolescent survivors of pediatric cancer are at high risk for executive functioning late effects (Butler & Mulhern, 2005; Winick, 2011). Attention difficulties tend to be the most frequently cited deficit, while difficulties in working memory, visual processing, general cognitive skills, and academic functioning are also common (Butler & Copeland, 2002; Butler & Mulhern, 2005; Campbell et al., 2007; and Raymond-Speden et al., 2000). As a result, it was

expected that the youth who participate in this study would likely have more difficulty with executive functioning than their peers.

Hypothesis 2b: Following the group intervention, the executive functioning of the participating youth would have improved as measured by the BRIEF self, parent, and teacher reports. Repeated measures t-tests were used to compare pre- and post-intervention BRIEF scores gathered from self, parent, and teacher reports to determine if the differences were statistically significant.

Rationale: Cognitive remediation has shown to be effective in increasing participants' knowledge of learning strategies and improving parent reported measures of attention (Butler et al., 2008). While Butler's intervention was presented individually to children over an extended period of time, it was expected that this intervention, which included nine group sessions over three months, would also lead to improvements in executive functioning skills due to the increased participation of parents and teachers to help youth generalize the skills.

Research Question 3: What was the pre-intervention level of parental stress? What impact did the combined CRT/CBT group have on the parental stress?

Hypothesis 3a: It was hypothesized that the parental stress levels for the parent participants, as measured by the PSI/SIPA, would be above the mean in the pre-intervention assessment. Basic descriptive statistics were used to determine the level of parental stress as noted by elevations in the 85th percentile or higher on the overall Total Parenting Stress score on the PSI/SIPA.

Rationale: There is significant stress for parents and family members related to childhood cancer diagnosis, treatment, and survivorship, as there is worry about treatment options, side effects, and relapse (Bayat et al., 2008). Treatment is often time-consuming and a financial burden, which can lead to further distress, particularly as many parents lose their jobs in order to care for their child. As a result of these stressful situations, parents are at elevated risks for depression, anxiety, and PTSD (Bayat et al., 2008). Thus, it was expected that parents would have higher stress levels than their peers.

Hypothesis 3b: Following the group intervention, the parental stress of the participating parents would have decreased. Repeated measures t-tests were used to compare pre- and post-intervention ratings of the PSI/SIPA completed by parents to determine if the differences were statistically significant.

Rationale: Adult support groups have led to improvements in overall distress (Pai et al., 2006) as well as depression, anxiety, and quality of life for members (Zabalegui et al., 2005). Studies have found that participating in a group with others who have experienced a similar situation can lead to feelings of support and encouragement for the individual (Johnson & Lane, 1993). Cognitive-behavioral therapy also leads to improvements in internalizing disorders, through the teaching and practicing of coping and problem-solving skills (Beck, 1995). It was expected that the parent group, which provided general support as well as psychoeducation about healthy coping and problem-solving, would have a positive effect on parent stress.

Research Question 4: What was the relationship between parental stress and youth psychological functioning?

Hypothesis 4A: There was an inverse relationship between parental stress and youth psychological functioning. A correlation was conducted between the parental stress level, as measured by the PSI/SIPA, and the participants' psychological functioning, as measured by the BASC-2, at pre-intervention to determine the relationship before the intervention.

Hypothesis 4B: Following the group intervention, the inverse relationship between parental stress and youth psychological functioning would continue to be present. Thus, as parental stress decreased, youth psychological functioning improved. A correlation was conducted to determine the change in functioning at pre-intervention and post-intervention of the parental stress level, as measured by the PSI/SIPA, and the participants' psychological functioning, as measured by the BASC-2.

Rationale: While few studies have indicated that decreases in parental stress lead to improvements of youth psychological functioning, research has established the relationship between family functioning or parental distress and youth adjustment (Ljungman et al., 2003; Robinson et al., 2007). Accordingly, it stands to reason that if parental stress were to decrease, family functioning would likely improve, and youth psychological functioning would also improve.

Research Question 5: What qualitative themes were present in the parent group?

Rationale: Following the qualitative methods approach (Creswell, 2009), hypotheses were not be made. A thematic analysis was conducted to examine the themes that were present in the parents' group.

Research Question 6: How did the youth and parents perceive the various aspects of the group intervention and its overall impact?

Rationale: Again, based on the qualitative methods approach (Creswell, 2009), hypotheses were not be made as the information from the youth and parent participants would lead to a theory or understanding of their experiences. However, the following three questions were been developed in order to narrow the larger research question.

a. How do the youth perceive the group intervention and its impact on their psychological and executive functioning?
b. How do the parents perceive the youth's group intervention and its impact on their children's psychological and executive functioning?
c. How do the parents perceive the parent support group and its impact on their parental stress?

Research Question 7: Were the measures of psychological and executive functioning in the quantitative component consistent with the themes present in the qualitative data?

Hypothesis 7: It was expected that the results from the two types of data inquiry would be consistent.

Rationale: Given that the quantitative and qualitative components measure the same larger construct, it was expected that they would be consistent.

Chapter 3: Method

The following chapter will include a description of the mixed methods research design as well as the advantages and disadvantages associated with it. In addition, information about the participants, instruments, and overall method will be reviewed. Finally, details about the quantitative and qualitative analyses will also be outlined.

Overview of Mixed Methods

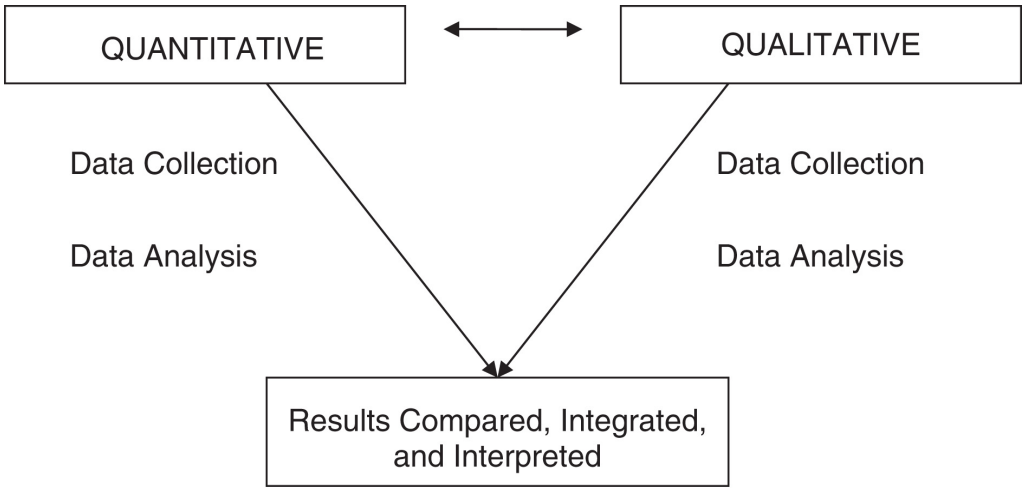
Mixed methods studies, or those that incorporate both quantitative and qualitative components, are thought to have originated in the middle of the twentieth century with Campbell and Fiske's analysis (1959) of the validity of psychological traits (Creswell, 2003). They encouraged the use of what they described as a "multitrait-multimethod matrix" in studies in order to maximize validity (Campbell & Fiske, p.81). In the 1970s, the use of mixed methods increased as researchers preferred a combination of methods to minimize the limitations present when quantitative or qualitative methods were used independently (Creswell, 2003). Over the last twenty years, research studies employing mixed methods have become more common, leading to the development of guidelines and strategies for their use (Creswell, 2009).

The major strength of a mixed methods approach is that it allows for a broader understanding of research phenomenon due to integrating both quantitative and qualitative approaches (Creswell, 2009). For example, one technique can be initially used to gather information and then a contrasting technique can be added to deepen the understanding of the results (Creswell). While the integration of a mixed methods approach allows for increased breadth and depth, it can also increase the amount of time

and amount of data needed. Thus, while mixed methods approaches can allow for a more thorough understanding of a phenomenon, they also need to be well planned given the intensity of the analysis (Creswell).

While this study includes both quantitative and qualitative components, the goal is to combine the results of each component, so that the data can be compared and contrasted to determine if results are consistent, following the concurrent triangulation strategy (Creswell, 2009), which is the most common of the mixed methods models. In the concurrent triangulation strategy (see figure 1 below, Concurrent Triangulation Method, 2011), equal weight is given to the quantitative and qualitative components (Creswell). This approach is advantageous given the relatively short time needed for data collection compared to the sequential models. Additionally, results tend to be well-founded since two modes of analysis are being compared. In this case, a combination of self-report measures and post-intervention interviews will be used to maximize the understanding of the impact of the combined CRT and CBT group for youth and their parents.

Figure 1: Concurrent Triangulation Method



Participants

Participants were 11 English-speaking children, along with 11 mothers and 11 teachers, who ranged in age from 9-15 and had received a cancer diagnosis. Ethnically, the youth participants were primarily Caucasian (63%), however 27% were Hispanic and 9% were Asian-American. The majority of the participants had completed treatment (10 of 11). One was receiving maintenance chemotherapy at the time of his participation in the intervention. The most common diagnosis was ALL (54% of participants), although there was a variety of other diagnoses as well (see Table 1). All participants attended at least partial days of school, according to their medical records. Most of the participants received school support, with 72% receiving support through a 504 accommodation plan and 18% receiving special education. Approximately half of the youth participants had been in individual or family-based therapy before the intervention.

Table 1

Participant Demographic Variables (N = 11)

Variable	Frequency	Percent
Gender		
Male	9	81.8
Female	2	18.1
Race/Ethnicity		
Caucasian	7	63.6
Hispanic	3	27.2
Asian-American	1	9.1
African-American	0	0
Biracial/Multi-Ethnic	0	0
Diagnosis		
Acute Lymphoblastic Leukemia	6	54.5
Medullablastoma	2	18.1
Burkitt Lymphoma	1	9.1
Synovial Sarcoma	1	9.1
Chronic Myelogenous Leukemia	1	9.1

Two other participants attended one session, but discontinued their participation due to financial and time constraints. In addition, one participant began the intervention,

but relapsed after the fourth session and did not return, given his medical fragility. The demographics of these three children were not included since they did not complete the entire intervention.

Instrumentation

Brief interviews

After the parent and child completed written consent and assent, they participated in a brief intake interview with the study coordinator. This interview was used to gather information about the child's medical and developmental history as well as academic and psychological functioning. The parent and child were also asked about any current academic or emotional concerns. At this time, the study coordinator completed a mental status exam and risk assessment with the child to determine if the child was eligible to participate in the group. No participants were excluded due to concerns about mental status or potential risk. An outline of the intake interview, mental status exam, and risk assessment can be found in Appendices C-E.

Each parent and child gave their consent and assent for a similar intake interview to be completed with one of the child's teacher (after he or she consented to participate) (see Appendices F and H). These interviews were led by the study coordinator or other research team member, and were used to gather information about the child's school performance, current academic accommodations, and specific goals set by the teacher, which could contribute to the child's academic success.

Behavior Assessment System for Children. The Behavior Assessment System for Children, 2nd Edition (BASC-2) consists of a series of individually-administered rating

scales for children and adolescents, ages 2-21, that are used to assist in diagnosis and classification of various emotional and behavioral disorders (Reynolds & Kamphaus, 2006). The BASC-2 includes two major components: clinical scales, which include various domains related to behavioral and emotional problems, and adaptive scales, which include various prosocial behaviors. Several versions of the BASC-2 have been developed for differing age groups, including preschool (2-5 years), child (6-11 years), and adolescent (12-21 years). For children and adolescents, the BASC-2 includes a parent version and self-report version. On all the scales, respondents indicate the frequency ("never", "sometimes", "often", or "almost always") of a particular behavior. In addition, on the two self-report versions, the youth respondents also indicate whether certain statements are "true" or "false".

The two parent versions (Parent Rating Scale – Child, PRS-C and Parent Rating Scale – Adolescent, PRS-A) include 160 and 150 items respectively, which comprise the following scales: Aggression, Anxiety, Attention Problems, Atypicality, Conduct Problems, Depression, Hyperactivity, Somatization, and Withdrawal (which make up the clinical scales) and Activities of Daily Living, Adaptability, Functional Communication, Leadership, and Social Skills (which make up the adaptive scales).

The child self-report version (SRS-C), which has 139 items, includes the following scales: Anxiety, Atypicality, Locus of Control, Social Stress, Attitude to School, Attitude to Teachers, Depression, and Sense of Inadequacy (which comprise the clinical scales) and Relations with Parents, Interpersonal Relations, Self-Esteem, and Self-Reliance (which comprise the adaptive scales). The adolescent self-report version

(SRS-A), which has 176 items, is very similar to the child-version and includes two additional scales, Sensation Seeking and Somatization, which are included in the clinical scales. Thus, the BASC-2 was developed in such a way that many scales can be compared across parent and youth raters. Within the clinical scales, higher scores indicate a high level of problem behavior, whereas on the on adaptive scales, higher scores indicate a higher level of functional behavior.

The BASC-2 was normed using a wide-range of children ages 2-18 and has high internal consistency (alpha ranging from 0.84 – 0.97) for all three versions (Reynolds & Kamphaus, 2006). All four versions of the BASC-2 appear to have adequate test-retest reliability as well, with correlations ranging from 0.83-0.92 for parents over a five-week period and 0.76-0.84 for self-report over a three-week period. In addition, the versions of the BASC-2 used in this study have adequate validity as they were highly correlated with corresponding measures (e.g. Achenbach System of Empirically Based Assessment, Connors' Parent Rating Scale – Revised/Connors-Wells' Adolescent Self-Report Scale).

Behavior Rating Inventory of Executive Function. Executive functioning was assessed using the Behavior Rating Inventory of Executive Function (BRIEF), which was developed in 2000 for children and adolescents ages 5-18 (Gioia, Isquith, Guy, & Kenworthy, 2000). The BRIEF examines eight domains of executive functioning including inhibition, shifting ability, emotional control, initiation, working memory, plan/organizational ability, organization of materials, and monitoring ability. These eight domains are then grouped into two indexes, Behavioral Regulation (which includes the first three scales) and Metacognition (which includes the remaining five scales). A

Global Executive Composite score is also determined, which is composed of all eight scales. The BRIEF includes a self-report version (available for youth ages 11-18) as well as parent and teacher versions (available for ages 5-18), all of which were used in this study. Respondents indicate the frequency ("never", "sometimes" or "often") at which they (or their child or student) exhibit a behavior. For example, a parent would indicate how often their child "becomes overwhelmed by large assignments" as well as "has trouble remember things, even for a few minutes." Two validity scales are also embedded in the measure, which examine the respondent's consistency in response style as well as negativity. The 86-item measure typically takes 15 minutes to complete and higher scores indicate that increased difficulty in that domain.

The parent and teacher versions of the BRIEF were normed on approximately 1400 parents and 700 teachers from a variety of areas across the United States, which was reflective of the 1999 U.S. Census for gender, ethnicity, and social economic status. In addition, norms were established for various clinical populations including children and adolescents with ADHD, traumatic brain injury, brain lesions, and other developmental disorders. All versions of the BRIEF appear to have adequate reliability. The parent and teacher versions of the BRIEF have high internal consistency (Cronbach's alpha coefficients ranged from 0.80 to 0.98) and the adolescent self-report version has moderate to high internal consistency (0.72-0.96) (Gioia, et. al, Guy, Isquith, Gioia, 2004). All versions of the BRIEF appear to have adequate test-retest reliability as well, with correlations of 0.76-0.85 for parents over a two-week period, 0.83-0.92 for teachers over a four-week period, and 0.59-0.85 for adolescents over a four-week period. All versions

of the BRIEF also have adequate validity as they were highly correlated with corresponding measures (e.g. ADHD Rating Scale-IV, CBCL, BASC).

The Parenting Stress Index - Short Form (PSI-SF; Abidin, 1995). The PSI-SF is a form completed by parents of children ages 1-12 years that consists of 36 items derived from the original PSI. It is composed of three scales: Parental Distress, Difficult Child Characteristics, and Dysfunctional Parent-Child Interaction and demonstrates good validity. In general, items are scored using the following 5-point scale: 1) SA (Strongly Agree), 2) A (Agree), 3) NS (Not Sure), 4) D (Disagree), and 5) SD (Strongly Disagree). According to Abidin (1995), this measure has good reliability based on a sample size of 800 parents of children (alpha ranging from 0.85 to .91) and is highly consistent with the full-length PSI ($r = 0.94$), which has good validity.

Stress Index for Parents of Adolescents. The Stress Index for Parents of Adolescents (SIPA) is a self-report measure completed by parents to evaluate areas of stress in the adolescent/parent relationship (Sheras, Abidin, & Konold, 1998). The SIPA contains 112 items, 90 items that are scored on a five-point scale (Strongly Agree, Agree, Not Sure, Disagree, Strongly Disagree) and 22 items that require a true or false response. The SIPA is composed of five domains: Adolescent domain, Parent domain, Adolescent-Parent domain, Life Stress scale, and Total Parenting Stress. It generally takes 20 minutes in total to complete. It requires a 5^{th} grade reading level and is normed for parents of adolescents ages 11-19. The SIPA was developed as an adolescent version of the Parent Stress Index, which is a commonly used measure of parental stress. The SIPA has adequate reliability, with internal consistency for the various subscales above 0.80

and alphas for the domains above 0.90. Test-rest reliability is also well established with correlations of 0.74-0.91 for parents over a four-week period.

Client Satisfaction Questionnaire. The Client Satisfaction Questionnaire (CSQ-8) is an eight-item self-report measure completed by patients to evaluate their satisfaction with a therapy intervention (Attkisson & Dwick, 1982). Items are rated on a four-point scale and are summed together with the higher scores indicating greater satisfaction. A sample item reads, "How satisfied are you with the amount of help you have received?" with the following options: quite dissatisfied (1), indifference or mostly satisfied (2), mostly satisfied (3), or very satisfied (4). The CSQ-8 has been used quite often with both adults and youth (Mah, Tough, Fung, Douglas-England, & Verhoef, 2006; Garland & Besinger, 1996), and has a reading level of grade 4.7 (Attkisson, & Greenfield, 1999). The CSQ-8 has been translated into many languages, including Spanish (Roberts & Attkisson, 1983), and has been found to have consistent results when used with a diverse group of clients, including those with Caucasian, African-American, and Hispanic backgrounds (Roberts & Attkisson, 1983). The CSQ-8 appears to have adequate reliability and validity. The internal consistency was 0.93 for a group of 248 mental health clients from five settings (Roberts & Attkisson, 1983). Concurrent validity was found to be adequate as the CSQ-8 was moderately correlated with therapists' self-ratings of satisfaction, as well as therapists' ratings of clients' satisfaction (Roberts & Attkisson, 1983).

Post Intervention Interview

After the children and parents participated in the intervention, individual interviews were conducted with each child and parent by the author and other research team members to gather information about their overall experience of the intervention. In order to minimize interviewer bias and reflexivity (Corbin & Strauss, 2008), the interviewers were not present for the intervention sessions and functioned only as a research assistant. Questions were asked to assess the participants' overall view of the intervention, perception of change, and feedback for improvement. Please see Appendices J-K for the interview questions.

Procedure

IRB Approval

The research study received approval from the Institutional Review Board (IRB) at the University of Texas at Austin on August 29, 2011 and was renewed on August 29, 2012. The study also followed the ethical standards established by the American Psychological Association and the University of Texas at Austin.

Youth and Parent Recruitment

Participants were recruited through one of two clinics, *'Specially for Children Blood and Cancer Center of Central Texas* (SCBCC) or the *Texas Child Study Center* (TCSC). These clinics worked in a collaborative partnership to provide effective treatment for children and adolescents diagnosed with cancer and/or blood disorders. Recruitment of families occurred at both sites and recruitment was conducted in a similar manner across sites. A flyer was developed which outlined the purpose of the group and

described other logistical information (see Appendix A). This flyer was shared with families that met the participation criteria following regularly scheduled visits to the social worker at SCBCC or psychologists or psychiatrists at TCSC. The families were encouraged to let the clinician know if they wanted to be contacted by the group coordinator for additional information. Upon interest from the family, the clinician obtained verbal consent to share the family's contact information with the study coordinator. Lists of interested families were developed at both SCBCC and TCSC and this information was shared with the study coordinator periodically.

Once interested families were identified, the study coordinator or another research team member made individual contact with the parent over the phone. Introductory information about the group was provided and the parent had an opportunity to ask questions about their participation (see phone script in Appendix B). Research team members were available to speak to the youth as well, if they had any questions about the group or wanted to hear information about it directly from a research team member. If the parent and child were interested in participating in the group, an initial meeting was set up with the coordinator or other research team member in order to obtain informed consent from the parent and assent from the child. Before the end of the call, the research team member notified the parent that their attendance at the initial meeting did not require them to participate in the group.

At the initial meeting, the study coordinator reviewed the parental consent forms and child assent forms with the parent and child. The parent also completed a Protected Health Information (PHI) form, which allowed the coordinator to gather specific

information about the child's medical record, including previous neuropsychological test results, specific diagnoses, dates of treatment, and medical clearance to attend school. The parent was notified that if they did not consent to audio recording, then they would not be able to participate in the group.

The study coordinator reviewed the medical information gathered about the child in order to determine if the child was eligible to participate in the study. In addition, the coordinator contacted the child's medical team, which included the oncologist, social worker, and nurse, to determine if the child was medically stable and had adequate cognitive ability to benefit from the group. Once the child was cleared to participate, an initial intake meeting with the child, the parent, and the study coordinator was planned. At this initial intake meeting, the study coordinator conducted the intake interview, mental status exam, and risk assessment to gather additional information about the child's medical, psychological, and academic background and current psychological functioning.

Teacher Recruitment

Teacher recruitment occurred after the parent and child provided their respective consent and assent. The parent and child were asked to identify a teacher who knew the child well and provided direct classroom instruction. If the child received special education services, the teacher who managed the student's individualized education plan was often recommended. Once the teacher was been identified, the parent provided signed permission for the coordinator or research team member to contact the identified teacher. The parent and child were also encouraged to notify the teacher that a researcher would contact him or her. The coordinator or research team member contacted the

teacher via phone or email to review the study and explain the desired involvement of the teacher. The informed consent was then mailed to the teacher for the teacher to review and send back (see Appendix G). The teacher was encouraged to contact the researcher with any questions.

Data collection

Pre-intervention data collection

Within a week of the beginning of the group intervention, the child and parent completed several measures independently, including the self-report or parent versions of the BRIEF and BASC-2. Parents also completed the PSI or SIPA. Critical items on the BASC-2, those which refer to suicidal ideation and psychotic disturbance, were reviewed by the study coordinator on the date of completion before the child and parent left the clinic. The identified teachers were also mailed the teacher version of the BRIEF and were asked to complete it and return it, via mail, to the study coordinator within a week of the beginning of the intervention.

Mid-intervention data collection

Members of the research team contacted teacher participants halfway through the intervention in order to share information about the group, including the child's progress and inquired about the child's performance at school. This contact occurred over the phone or via email, depending on the teacher's preference.

Post-Intervention Data Collection

Following conclusion of the group intervention, youth and parents completed appropriate versions of the BRIEF and BASC-2. Parents also completed the PSI or

SIPA. As in the pre-intervention data collection phase, the study coordinator examined critical items on the BASC-2 on the date of completion before the child and parent left the clinic. The child and parent also met individually with one of the research assistants for the post-intervention interview. Teachers were mailed the teacher version of the BRIEF along with a stamped envelope in order for them to complete the measure and return it to the researchers. Once the BRIEF has been received, a letter was sent to the teachers thanking them for their participation in the study (see Appendix I).

Intervention

The intervention included approximately nine 90-minute group therapy sessions. The youth and parents met in two separate groups for approximately the first 60 minutes and groups were combined during the last 30 minutes. The child group was led by at least two research team members and was focused on teaching the youth the psychological and executive functioning concepts and strategies listed below. Parent group sessions were led by at least one research team member and reviewed the skills that the children learned in order for the parents to support their children in using these strategies. The parent group also provided time for the parents to discuss their experiences raising children with cancer and support one another. The combined group session time was focused on a review of the strategies and a discussion of how these strategies could be generalized at home and school. Homework was assigned for the youth and the parents were encouraged to help their child remember to complete it over the following week.

Session One: Increasing Sustained Attention "Body Check". The first session highlighted the importance of sustained attention. The group began by establishing group rules, playing several name games, and helping the participants to get to know one another. After a brief discussion of attention, the group participated in an activity, modified from the ACTION program (Stark et. al., 2006), which demonstrated that the youth had control over their attention. Finally, the concept of "body check" was introduced to highlight the importance of checking their body to determine if they were paying attention. The six body parts were discussed using the following phrase, "eyes, ears, nose, mouth, bottom, toes", which cued the participants to consider those body parts and whether they were engaging in behavior that would help them be attentive (e.g. looking at the speaker). The youth were asked to practice the body check outside of group and practiced the phrase several times to ensure that they remembered it. The youth were also introduced to a memory strategy to assist them in remembering the attention strategies. In following sessions, additional memory strategies and reminders about the attention strategies were introduced, in order for the youth to generalize the attention and memory strategies to home and school. The session was reviewed with parents, highlighting the strategies for sustained attention.

Session Two: Basics of Cognitive Behavior Therapy. Since many adolescent survivors of cancer experience distress and elevated levels of anxiety (Askins & Moore, 2008), the second session introduced the fundamentals of Cognitive Behavioral Therapy, starting with affective education. The adolescents were taught the importance of identifying their emotions using cognitive and physiological cues, in order to be able to

use coping skills to modify their emotions by changing their thoughts and behaviors. Various emotions were discussed including frustration, sadness, anger, and boredom. They also reviewed the "body check" for attention and introduced "Boomerang it back" to highlight the importance of shifting attention when the youth realize that they have become distracted.

Sessions Three, Four, & Five: The next three sessions focused on coping skills. Six different types of coping skills were taught, loosely based on the ACTION program, including distraction, using energy, relaxation and mindfulness, seeking social support, spirituality, and thinking positively (Stark et. al., 2006). Participants discussed situations in which coping would be appropriate and practiced using the skills during session as well as at home and school in order to guarantee that these skills generalize outside of group. The participants were also introduced to the idea of mindfulness and how it relates to attention. Finally, they were taught several memory strategies (e.g. mnemonics, mental imagery, and chunking), which they were encouraged to use at home and school. All of these skills were also introduced to the parents in the parent group and a joint review occurred at the end of the sessions.

Sessions Six, Seven, & Eight: Problem Solving "5 P's". Problem solving can be an effective way to solve academic and social problems (NASP, 2002). The five steps of problem solving, or the 5 P's, were introduced to the youth, based on the ACTION manual (Stark et. al., 2006). The steps included identifying the problem, thinking about the purpose or desired outcome, brainstorming various solutions or plans, predicting the outcome of each plan and choosing one, and then praising yourself for using the strategy.

Several examples were discussed together and the group collaboratively practiced using the five steps. Each week focused on problem solving in a particular facet of their life: school (organization, planning, grades, missing assignments, etc.), peers (being forgetful in social situations, getting along with peers, etc.), and related to their medical condition. The adolescents were asked to practice the five steps individually throughout the week in order for them to become more comfortable using the skills independently. They were also introduced to the idea of cognitive flexibility and perspective taking in the eighth session. Parents continued to join the sessions and reviewed problem solving.

Session Nine: Wrap up and Review of all concepts. The youth were each provided with a binder that summarizes all the concepts that were covered over the nine weeks. The binder also contained specialized sections, such as a calendar section and a homework assignment section, to assist the adolescents in applying the concepts they learned in group to their academic environments. The adolescents then participated in a game in order to review concepts from the group and discussed relevant examples. Following this, the youth and parents met together for a final review of the intervention.

Lumosity

An additional component was added to the intervention for the fourth and fifth cohorts, which included participation in a computer-based cognitive remediation program called Lumosity. Lumosity was designed by Lumos Labs, Inc. to treat the neurocognitive and meta-cognitive late effects/disturbances. Participants practiced and further developed cognitive skills including cognitive flexibility, sustained attention, and working memory through their participation in Lumosity. Participants were asked to complete 5 Lumosity

sessions a week, over eight weeks, with the goal of completing 40 sessions. The majority of participants in the fourth and fifth cohorts were able to complete the 40 sessions during the intervention. Each session included several online games, which could be completed in approximately 20 minutes. Exercises were adaptively hierarchical with the difficulty level adjusting to the participants' performance and immediate feedback was provided regarding accuracy of responses. An introduction to the program was included in the first session and time was spent in both the youth and parent groups to discuss problem solving to ensure that the participants were able to meet the goal of completing five sessions a week.

Data Analysis

Pilot Study

The intervention was piloted in the spring 2011 in order to gather information about the clinical impact of the group, following the Texas Child Study Center's preference of using evidence-based interventions. Five children and six parents (the mother and father of one adolescent participated) comprised the pilot study. Youth ranged in age from 12-17 years old and were in grades 6-11.

A brief review of the quantitative data suggested that the intervention led to small changes in psychological and executive functioning of several participants. Due to the small sample size, only an informal review of the pre and post measures was completed. However, changes were found for three of the five children. Specifically, the parents' report of psychological functioning, as measured by the BASC-2, appeared notable for three adolescents. In addition, notable changes appeared for the self-report executive

functioning measure (BRIEF) for two adolescents. Finally, no notable changes were found for one adolescent and the pre-intervention data for the final participant was not accessible at the time of analysis.

A brief qualitative analysis of the parent sessions and post-intervention interviews was completed and several themes were present. Within the parent sessions, one theme that parents expressed was the challenge of balancing the needs of their child who had cancer with the needs of the remaining family members, particularly other children. Similarly, the parents described a high level of stress and few opportunities to rejuvenate themselves. Other themes for the parent group included feelings of uncertainty about appropriate expectations for their child who had cancer, both in an academic framework, and in the adolescent's behavior at home. Finally, parents expressed a desire to return to normalcy, yet acknowledged fears related to this transition. These themes were brought up within the later parent support groups, as they were relevant for all parents of pediatric cancer survivors.

In the post-intervention interviews, both the youth and parents acknowledged that the group intervention helped them to feel understood by others and that they enjoyed meeting other people who could relate to their perspective.

Quantitative Data Analysis

Quantitative analysis was used to evaluate the first three hypotheses using IBM SPSS version 21. Given the content differences between cohort 2 and 3 compared to 4 and 5, t-tests were run to determine if the two groups were significantly different from one another. The following variables were compared, including the following clinical

and adaptive scales from the BASC-2 (Parent Internalizing, Parent Externalizing, Parent Behavioral Symptoms, Parent Adaptive Skills, Youth Internalizing, Youth School, and Youth Personal Adjustment), the two indexes and overall score from the BRIEF (Global Executive Composite, Metacognition, and Behavioral Regulation from parent, teacher, and child raters), and the overall PSI and SIPA scores (PSI Total Stress and SIPA Index of Total Parenting Stress).

Repeated measures t-tests were run to determine significant differences between pre- and post-measures. A Spearman's rank-order correlation was calculated to assess the relationship between parental stress, as measured by the PSI or SIPA, and psychological functioning, as measured by the BASC-2, because the data did not appear to be linear.

Hypothesis 1a: It was hypothesized that the psychological functioning of the participating youth, as measured by the BASC-2 self and parent reports, would be above the mean for the clinical scales and below the mean for the adaptive scales in the pre-intervention assessment data. Individual pre-intervention BASC-2 scores were compared to the 90% confidence interval of the general normative sample, based on participants' gender and age. In addition, descriptive statistics were used to determine if the pre-intervention scores were in the "at risk" range (T score of 60-69 for clinical scales and 31-40 for adaptive scales) or "clinically significant" range (T score of 70 or greater for clinical scales and 30 or below for adaptive scales).

Hypothesis 1b: Following the group intervention, the psychological functioning of the participating youth would have improved. Specifically, it was expected that the parent and youth report of youth psychological functioning as measured by the BASC-2

would be significantly lower for the clinical scales and higher for the adaptive scales. Repeated measures t-tests were used to compare pre- and post-intervention BASC-2 scores gathered from the self and parent reports to determine if the differences were statistically significant.

Hypothesis 2a: It was hypothesized that the participating youth would have deficits in their executive functioning in the pre-intervention assessment, as measured by scores above the mean for self, parent, and teacher reports on the BRIEF. Individual pre-intervention BRIEF scores were compared to the 90% confidence interval of the general normative sample, based on participants' gender and age. In addition, descriptive statistics were used to determine if the pre-intervention scores were in the "clinically significant" range, as noted by a T score of 65 or higher.

Hypothesis 2b: Following the group intervention, the executive functioning of the participating youth would have improved as measured by the BRIEF self, parent, and teacher reports. Repeated measures t-tests were used to compare pre- and post-intervention BRIEF scores gathered from self, parent, and teacher reports to determine if the differences were statistically significant.

Hypothesis 3a: It was hypothesized that the parental stress levels for the parent participants, as measured by the PSI/SIPA, would be above the mean in the pre-intervention assessment. Basic descriptive statistics were used to determine the level of parental stress as noted by elevations in the 85th percentile or higher on the overall Total Parenting Stress score on the PSI/SIPA.

Hypothesis 3b: Following the group intervention, the parental stress of the participating parents would have decreased. Repeated measures t-tests were used to compare pre- and post-intervention ratings of the PSI/SIPA completed by parents to determine if the differences were statistically significant.

Hypothesis 4A: There was an inverse relationship between parental stress and youth psychological functioning. A correlation was conducted between the parental stress level, as measured by the PSI/SIPA, and the participants' psychological functioning, as measured by the BASC-2, at pre-intervention to determine the relationship before the intervention.

Hypothesis 4B: Following the group intervention, the inverse relationship between parental stress and youth psychological functioning would continue to be present. Thus, as parental stress decreased, youth psychological functioning improved. A correlation was conducted to determine the change in functioning at pre-intervention and post-intervention of the parental stress level, as measured by the PSI/SIPA, and the participants' psychological functioning, as measured by the BASC-2.

Qualitative analysis

A thematic analysis was conducted to examine the themes that were present in the parents' group using audiotapes. The decision was made to focus on the parents group since the intervention for parents was somewhat less structured and designed to allow parent participants to share their preferences of discussion topics and have more ownership in the group process.

Secondly, qualitative interviews were conducted with youth and parent participants in order to understand the participants' view of the group intervention, the main research question was: How do the adolescents and parents perceive the various aspects of the group intervention and its overall impact? Interviews were guided by several general questions.

1. How do the adolescents perceive the group intervention and its impact on their psychological and executive functioning?
2. How do the parents perceive the adolescents' group intervention and its impact on their children's psychological and executive functioning?
3. How do the parents perceive the parent support group and its impact on their parental stress?

A general content analysis was conducted to learn about the themes present across the four parent cohorts. Following the method described by Corbin and Strauss (2008), the sessions were first listened to and thorough notes were made in order to gather an initial understanding of the material. Then the author read through the summaries several times to consider initial themes, using open coding. Notes were then taken, in the form of short memos, about the initial themes and how they might be linked together. Axial coding was then used as the themes were grouped into larger categories and the relationship between the themes was considered. Throughout this process, constant comparison was made between different data points to consider how themes were similar and different from one another, especially with respect to themes present in the four

various parent cohorts. The author also reviewed the audiotapes of notable sessions multiple times in order to select quotes.

Content analysis was also used to understand the youth and parent participants' perspectives on the intervention. The interviews were transcribed and read by the author. She then took notes on the initial themes that emerged as she read and re-read the transcripts. These themes were then further analyzed in order to determine the larger relationship between the themes. Comparisons were also made between the youth and parent perspectives.

Several techniques were considered to improve the trustworthiness of this study, based on Lincoln and Guba's work (1985). First, following the principle of prolonged engagement, the author listened to all of the parent group sessions over nine weeks for four cohorts. While the author did not participate in the youth or parent groups across the four cohorts, she was present for the youth sessions for the pilot group in order to have a basis for understanding the unique cultural aspects of this group. Similarly, the technique of persistent observation was used as each cohort met for approximately nine sessions for 60-90 minutes per session, which allowed for significant depth of conversation. The research coordinator and group leaders also discussed with the participants the rationale behind the sessions being audiotaped as well as the post-intervention interview in order to help them feel comfortable with the process and be more likely to be honest in their responses. Finally, as described below, triangulation of the qualitative and quantitative data was completed in order to increase the credibility of the results.

Triangulation

Following the concurrent triangulation approach, the data from the quantitative and qualitative analyses was triangulated, or compared, to determine if the results were consistent (Creswell, 2009). The data set was transformed in one of two ways based on Onwuegbuzie and Teddlie's (2003) seven-step model (Johnson & Onwuegbuzie, 2004). The qualitative data can be transformed into a quantifiable version, by assigning numerical codes to the themes, or the quantitative data can be rewritten in a narrative format to compare to the qualitative data. The data was then compared directly and consistencies and differences are noted and discussed. These methods were used in order to address the final research question:

Are the measures of psychological and executive functioning in the quantitative component consistent with the themes present in the qualitative data?

Summary

In summary, this chapter discussed the mixed methods research design used in this study of the impact of a combined cognitive remediation and cognitive behavioral therapy group on youth and their families. The method was described in detail and the quantitative, qualitative, and triangulated analyses were reviewed.

Chapter 4: Results

Quantitative Analysis

Missing data

Missing data from the five measures was evaluated in order to determine what data was available for analysis (see table 2). All youth and parent participants completed the BASC-2. All parent participants completed the BRIEF, however three youth did not complete the BRIEF because they did not meet the age requirement of 11 years or older. One of these children was in cohort 3 and the other two were in cohort 4. In addition, six of the teachers did not complete the BRIEF post-intervention, thus the scores were not included. These six missing post-intervention teacher BRIEF were spread across the four cohorts (1 from cohort 2, 2 from cohort 3, 2 from cohort 4, and 1 from cohort 5). It appears that many teachers did not return the BRIEF, despite multiple reminders from research team members.

The PSI was completed by all four parents that met the age requirement for their children. The SIPA was completed by five of the seven parents. The pre and post-intervention SIPA from a parent in cohort 2 was lost, thus it was not included. In addition, one parent from cohort 4 completed the data post-intervention, but was pre-intervention data was not found. Finally, the CSQ was completed by all but one parent, who was in cohort 3. The CSQ was completed by all participants in cohorts 2, 4, and 5, but was not completed by either child participant in cohort 3.

Table 2

Summary of Collected Data

Measure	Parent Report	Self Report	Teacher Report
BASC-2	11	11	n/a
BRIEF	11	8	5
PSI	4	n/a	n/a
SIPA	5	n/a	n/a
CSQ	10	9	n/a

Combining Data

Quantitative analysis was used to evaluate the first three hypotheses using IBM SPSS version 21. Independent samples t-tests were conducted to determine if the data from the two sets of cohorts could be combined given the difference of the inclusion of the Lumosity component in the fourth and fifth cohorts (see tables 3 - 8). Statistical significance was not found for any comparison, thus the pre-intervention and post-intervention results from the groups were combined. Levene's test for equality of variance was significant for one group (pre-intervention BASC-2 youth internalizing clinical scale), so the reported values are based on unequal variance. In addition, the comparison of post-intervention BRIEF teacher measures could not be commuted, as there were not any post-intervention scores for cohort 2 and 3.

Table 3

BASC-2 Pre-Intervention Comparison for Cohorts 2 and 3 with 4 and 5

Scale	N	Mean	SD	t	df	Sig. (2-tailed)
Parent Internalizing						
Cohort 2 & 3	4	46.75	9.91	-.480	9	.642
Cohort 4 & 5	7	49.43	8.34			
Parent Externalizing						
Cohort 2 & 3	4	49.25	10.72	-.410	9	.691
Cohort 4 & 5	7	51.71	8.96			
Parent Behavioral Symptoms						
Cohort 2 & 3	4	49.25	10.78	-.952	9	.366
Cohort 4 & 5	7	54.43	7.41			
Parent Adaptive Skills						
Cohort 2 & 3	4	48.50	13.07	.912	9	.385
Cohort 4 & 5	7	42.43	9.14			
Youth Internalizing						
Cohort 2 & 3	4	54.75	15.35	1.271[a]	3.54[a]	.281[a]
Cohort 4 & 5	7	44.57	6.05			
Youth School						
Cohort 2 & 3	4	50.50	6.61	.732	9	.483
Cohort 4 & 5	7	47.57	6.27			
Youth Personal Adjustment						
Cohort 2 & 3	4	44.75	17.63	-1.624	9	.139
Cohort 4 & 5	7	56.29	6.10			

[a] Levene's test for equality of variance was significant, so reported values are based on unequal variance

Table 4

BASC-2 Post-Intervention Comparison for Cohorts 2 and 3 with 4 and 5

Scale	N	Mean	SD	t	df	Sig. (2-tailed)
Parent Internalizing						
Cohort 2 & 3	4	48.50	8.42	.921	9	.381
Cohort 4 & 5	7	43.14	9.67			
Parent Externalizing						
Cohort 2 & 3	4	50.75	10.18	.422	9	.683
Cohort 4 & 5	7	48.71	6.10			
Parent Behavioral Symptoms						
Cohort 2 & 3	4	51.00	9.49	.312	9	.762
Cohort 4 & 5	7	49.29	8.40			
Parent Adaptive Skills						
Cohort 2 & 3	4	48.00	11.46	.347	9	.737
Cohort 4 & 5	7	45.71	10.01			
Youth Internalizing						
Cohort 2 & 3	4	45.50	5.00	.894	9	.395
Cohort 4 & 5	7	42.29	6.07			
Youth School						
Cohort 2 & 3	4	53.25	6.34	1.992	9	.078
Cohort 4 & 5	7	45.14	6.57			
Youth Personal Adjustment						
Cohort 2 & 3	4	48.00	7.16	-.733	9	.482
Cohort 4 & 5	7	52.43	10.66			

Table 5

BRIEF Pre-Intervention Comparison for Cohorts 2 and 3 with 4 and 5

Scale	N	Mean	SD	t	df	Sig. (2-tailed)
Parent GEC						
Cohort 2 & 3	4	57.25	13.18	-1.042	9	.324
Cohort 4 & 5	7	64.43	9.71			
Parent Metacognition						
Cohort 2 & 3	4	60.50	13.69	-.552	9	.594
Cohort 4 & 5	7	64.71	11.34			
Parent Behav. Regulation						
Cohort 2 & 3	4	50.50	11.62	-2.177	9	.057
Cohort 4 & 5	7	60.71	4.07			
Youth GEC						
Cohort 2 & 3	3	54.67	16.80	1.367	6	.221
Cohort 4 & 5	5	43.20	7.53			
Youth Metacognition						
Cohort 2 & 3	3	58.33	16.26	1.416	6	.207
Cohort 4 & 5	5	45.80	9.39			
Youth Behav. Regulation						
Cohort 2 & 3	3	50.00	15.39	1.092	6	.317
Cohort 4 & 5	5	41.40	7.47			
Teacher GEC						
Cohort 2 & 3	4	62.50	9.57	-.256	9	.804
Cohort 4 & 5	7	64.43	13.09			
Teacher Metacognition						
Cohort 2 & 3	4	67.50	9.71	-.282	9	.784
Cohort 4 & 5	7	70.00	15.88			
Teacher Behav. Regulation						
Cohort 2 & 3	4	50.50	8.58	-.365	9	.723
Cohort 4 & 5	7	52.57	9.27			

Table 6

BRIEF Post-Intervention Comparison for Cohorts 2 and 3 with 4 and 5

Scale	N	Mean	SD	t	df	Sig. (2-tailed)
Parent GEC						
Cohort 2 & 3	4	57.25	16.28	-.216	9	.834
Cohort 4 & 5	7	59.00	10.88			
Parent Metacognition						
Cohort 2 & 3	4	59.75	17.58	-.028	9	.979
Cohort 4 & 5	7	60.00	12.54			
Parent Behav. Regulation						
Cohort 2 & 3	4	51.25	14.93	-.488	9	.637
Cohort 4 & 5	7	54.43	7.09			
Youth GEC						
Cohort 2 & 3	3	55.67	11.72	1.820	6	.119
Cohort 4 & 5	5	42.00	9.49			
Youth Metacognition						
Cohort 2 & 3	3	58.00	10.58	1.616	6	.157
Cohort 4 & 5	5	44.80	11.48			
Youth Behav. Regulation						
Cohort 2 & 3	3	52.33	11.01	1.801	6	.122
Cohort 4 & 5	5	39.40	9.18			

Table 7

PSI/SIPA Pre-Intervention Comparison for Cohorts 2 and 3 with 4 and 5

Scale	N	Mean	SD	t	df	Sig. (2-tailed)
PSI Total Stress						
Cohort 2 & 3	2	27.50	24.75	-3.39	2	.077
Cohort 4 & 5	2	87.50	3.54			
SIPA Index of Total Parenting Stress						
Cohort 2 & 3	1	78.00	n/a	.884	3	.442
Cohort 4 & 5	4	56050	21.75			

Table 8

PSI/SIPA Post-Intervention Comparison for Cohorts 2 and 3 with 4 and 5

Scale	N	Mean	SD	t	df	Sig. (2-tailed)
PSI Total Stress						
Cohort 2 & 3	2	20.00	21.21	-2.49	2	.130
Cohort 4 & 5	2	65.00	14.14			
SIPA Index of Total Parenting Stress						
Cohort 2 & 3	1	75.00	n/a	1.447	3	.244
Cohort 4 & 5	4	47.50	17.00			

Main analysis

Repeated measures t-tests were completed to determine significant differences between pre- and post-measures, including the BASC-2, BRIEF, SIPA, and PSI. To check for the assumption of univariate normality, box plot graphs were generated. Two Youth Personal Adjustment scores on the BASC-2 were identified as being outliers based on the box plots. As a result the 5% trimmed mean was examined. The 5% trimmed mean of the difference -1.56 was not significantly different from the overall mean of -1.4. Therefore, it was decided to retain these outliers in the analyses. Therefore, the assumptions of univariate normality and outliers were met.

A Spearman's rank-order correlation was conducted to assess the relationship between parental stress, as measured by the PSI or SIPA, and psychological functioning, as measured by the BASC-2. Preliminary analysis showed the relationships to be monotonic, as assessed by visual inspection of the scatterplots.

Psychological Functioning

It was hypothesized that the psychological functioning of the participating youth, as measured by the BASC-2 self and parent reports, will be above the mean for the clinical scales and below the mean for the adaptive scales in the pre-intervention assessment data. Individual pre-intervention BASC-2 scores were compared to the 90% confidence interval of the general normative sample, based on participants' gender and age (see table 9). Depending on the item, 18-54% of the parent clinical scales and 18% of the youth clinical scales were above 90% confidence interval, whereas 63% of the

parent adaptive scales and 10% of the youth adaptive scales were below the 90% confidence interval.

Descriptive statistics were used to determine if the pre-intervention scores are in the "at risk" or "clinically significant" ranges, as noted by a T score of 60 or higher on the clinical scale and 40 or lower on the adaptive scale. For the parent clinical scales, 9-27% of the sample reached clinical significance, whereas 9-18% of the youth clinical scales met the same criteria. Finally, for the adaptive scales, 36% of the parent measures and 10% of the youth measures reached clinical significance.

Table 9

BASC-2 Pre-intervention Analysis (n = 11)

Scale	Above 90% CI		Clinical Significance	
	Frequency	Percent	Frequency	Percent
Parent				
Externalizing	3	27.1	3	27.1
Internalizing	2	18.1	1	9.0
Behavioral Symptom	6	54.5	3	27.1
Adaptive Skills[a]	7	63.6	4	36.3
Youth				
Internalizing	2	18.1	2	18.1
School	2	18.1	1	9.0
Personal Adjustment[a]	1	9.0	1	9.0

[a] Represents an adaptive scale, so higher scores indicate a strength

Repeated measures t-tests were performed to investigate the impact of the intervention, based on the pre- and post-intervention BASC-2 scores. The results (see

Table 10) indicated that there was a significant difference between the pre- and post-intervention BASC-2 scores for three scales. Parent ratings of youth internalizing symptoms decreased after the intervention, $t(10) = 2.153$, $p < 0.05$, and adaptive skills increased after the intervention, $t(10) = -2.013$, $p < 0.05$. Youth ratings of their own internalizing symptoms, $t(10) = 1.871$, $p < 0.05$, also decreased after the intervention. Descriptive statistics were used to determine if the post-intervention scores were in the "at risk" or "clinically significant" ranges (see table 11). For the parent clinical scales, 0-9% of the sample reached clinical significance, whereas 0-9% of the youth clinical scales met the same criteria. Finally, for the adaptive scales, 36% of the parent measures and 9% of the youth measures reached clinical significance.

Table 10

BASC-2 Paired Sample Tests

Scale	Mean[a]	SD	t	df	Sig. (1-tailed)
Parent Internalizing	3.364	5.182	2.153	10	.028*
Parent Externalizing	1.364	7.500	.603	10	.280
Parent Behavioral Symptoms	2.636	6.786	1.288	10	.113
Parent Adaptive Skills	-1.909	3.145	-2.013	10	.036*
Youth Internalizing	4.818	8.542	1.871	10	.045*
Youth School	0.545	7.090	0.255	10	.402
Youth Personal Adjustment	1.273	9.242	.457	10	.329

[a] Refers to mean difference between pre/post scores
* $p < .05$

Table 11

BASC-2 Post-intervention Analysis (n = 11)

Scale	Clinical Significance	
	Frequency	Percent
Parent		
Externalizing	0	0.0
Internalizing	1	9.0
Behavioral Symptom	1	9.0
Adaptive Skills[a]	4	36.3
Youth		
Internalizing	0	0.0
School	1	9.0
Personal Adjustment[a]	1	9.0

[a] Represents an adaptive scale, so higher scores indicate a strength

Executive Functioning

It was hypothesized that the participating youth would have deficits in their executive functioning in the pre-intervention assessment, as measured by scores above the mean for self, parent, and teacher reports on the BRIEF. The self, parent, and teacher reports of the BRIEF were examined to determine if the scores were higher than the mean for the overall Global Executive Composite (GEC) score and two broad indexes (Metacognition and Behavioral Regulation). The Metacognition index included Initiate, Working Memory, Plan/Organize, Organization of Materials, and Monitor; the Behavioral Regulation index included Inhibit, Shift, and Emotional Control; and GEC was drawn from all the eight subscales. Individual pre-intervention BRIEF scores were

compared to the 90% confidence interval of the general normative sample, based on participants' gender and age (see table 12). An evaluation determined that 63-72% of parent scales, 36-90% of teacher scales, and 12-25% of the youth scales were above the 90% confidence interval. Descriptive statistics were used to determine if the pre-intervention scores were in the "clinically significant" range, as noted by a T score of 65 or higher. Approximately 18-54% of parent scales, 9-54% of teacher scales, and 12% of youth scales reached clinical significance.

Table 12

BRIEF Pre-intervention Analysis

Scale	Above 90% CI		Clinical Significance	
	Frequency	Percent	Frequency	Percent
Parent (n = 11)				
GEC	8	72.7	5	45.4
Metacognition	8	72.7	6	54.5
Behavioral Regulation	7	63.6	2	18.1
Teacher (n = 11)				
GEC	9	81.8	4	36.3
Metacognition	10	90.9	6	54.5
Behavioral Regulation	4	36.3	1	9.0
Youth (n = 8)				
GEC	1	12.5	1	12.5
Metacognition	2	25.0	1	12.5
Behavioral Regulation	1	12.5	1	12.5

Repeated measures t-tests were performed to investigate the impact of the intervention, based on the pre- and post-intervention BRIEF scores. The results (see Table 13) indicated that there was a significant difference between the pre- and post-intervention BRIEF scores for three parent scales. Parent reports of youth behavioral regulation, $t(10) = 2.023$, $p < .05$, metacognition $t(10) = 1.825$, $p \leq 0.05$, and global executive composite, $t(10) = 1.937$, $p \leq 0.05$ decreased after the intervention. Descriptive statistics were also used to determine if the pre-intervention scores were in the "clinically significant" range (see table 14). Approximately 9-45% of parent scales, 0-40% of teacher scales, and 12% of youth scales reached clinical significance.

Table 13

BRIEF Paired Sample Tests

Scale	Mean[a]	SD	t	df	Sig. (1-tailed)
Parent Global Executive Composite	3.455	6.424	1.937	10	.052*
Parent Metacognition	3.273	6.051	1.825	10	.051*
Parent Behavioral Regulation	3.727	6.710	2.023	10	.047*
Youth Global Executive Composite	.375	4.173	1.475	4	.403
Youth Metacognition	.750	4.590	1.623	4	.329
Youth Behavioral Regulation	.375	4.340	1.535	4	.407
Teacher Global Executive Composite	-5.00	13.73	6.140	7	.230
Teacher Metacognition	-5.40	14.758	6.600	7	.229
Teacher Behavioral Regulation	-2.20	12.194	5.453	7	.353

[a] Refers to mean difference between pre/post scores
* $p \leq 0.05$

Table 14

BRIEF Post-intervention Analysis

Scale	Clinical Significance	
	Frequency	Percent
Parent (n = 11)		
GEC	3	27.2
Metacognition	5	45.4
Behavioral Regulation	1	9.0
Teacher (n = 5)		
GEC	2	40.0
Metacognition	2	40.0
Behavioral Regulation	0	0.0
Youth (n = 8)		
GEC	1	12.5
Metacognition	1	12.5
Behavioral Regulation	1	12.5

Parental Stress

The Total Stress index of the PSI and the Index of Total Parenting Stress of the SIPA were examined to determine if the scores were higher than the 50th percentile (see Table 15) as the standard deviation and standard error of measurement of the normative sample were not available. The mean of the PSI Total Stress was at the 57.5th percentile, which is slightly above the mean, but still in the typical range. Similarly, the mean of the Total Parenting Stress on the SIPA was 60.8, which is above the mean, but considered to be within normal limits.

Table 15

PSI and SIPA Pre-Intervention Means

Scale	Parent Report
PSI Total Stress	57.50
SIPA Index of Total Parenting Stress	60.80

Repeated measures t-tests were performed to investigate the impact of the intervention, based on the pre- and post-intervention PSI/SIPA scores. The results (see Table 16) indicated that there was a significant difference between the pre- and post-intervention PSI scores, $t(3) = 2.777$, $p < .05$ as well as SIPA scores, $t(4) = 2.053$, $p \leq 0.05$. Parental stress decreased after the intervention.

Table 16

PSI and SIPA Paired Sample Tests

Scale	Mean[a]	SD	t	df	Sig. (1-tailed)
PSI Total Stress	15.000	10.801	2.777	3	.034*
SIPA Index of Total Parenting Stress	7.800	8.497	2.053	4	.054*

[a] Refers to mean difference between pre/post scores
* $p \leq 0.05$

Parental Stress and Youth Psychological Functioning

A Spearman's rank-order correlation was run to assess the relationship between parental stress, as measured by the PSI or SIPA, and youth psychological functioning, as measured by the BASC-2. First, a correlation was calculated between the parental stress level, as measured by the PSI/SIPA, and the participants' psychological functioning, as measured by the BASC-2, at pre-intervention to determine the relationship before the intervention (see table 17). Results indicate that there was a strong positive correlation between youth internalizing symptoms as measured by parents and parental stress (as measured by the PSI), $r_s(4) = 1.00$, $p < .01$. There was a strong negative correlation between youth adaptive skills as measured by parents and parental stress (as measured by the PSI), $r_s(4) = -.800$, $p < .01$. Finally, there was a positive correlation between youth related of school and parental stress (as measured by the SIPA), $r_s(5) = .975$, $p < .05$.

A correlation was also conducted to determine the change in functioning at pre-intervention and post-intervention of the parental stress level, as measured by the PSI/SIPA, and the participants' psychological functioning, as measured by the BASC-2. Preliminary analysis showed the relationships to be monotonic, as assessed by visual inspection of a scatterplot. Results indicated (see table 18) that three of the fourteen correlations were statistically significant. There was a strong positive correlation between youth internalizing symptoms as measured by parents and parental stress (as measured by the PSI), $r_s(4) = 1.00$, $p < .01$. There was a strong negative correlation between youth adaptive skills as measured by parents and parental stress (as measured by

the PSI), $r_s(4) = -1.00$, $p < .01$. Finally, there was a positive correlation between youth behavioral symptoms as rated by parents and parental stress (as measured by the SIPA), $r_s(5) = .900$, $p < .05$.

Table 17

Correlations between Pre-Intervention PSI/BASC-2 and SIPA/BASC-2

BASC-2 Scales	PSI (n = 4)	SIPA (n = 5)
Parent Internalizing	1.000**	-.200
Parent Externalizing	.600	.300
Parent Behavioral Symptoms	-.316	.205
Parent Adaptive Skills	-.800**	.500
Youth Internalizing	-.400	.200
Youth School	.316	.975**
Youth Personal Adjustment	-.400	.400

* $p < .05$, **$p < .01$

Table 18

Correlations between the Change in PSI/BASC-2 and SIPA/BASC-2

BASC-2 Scales	PSI (n = 4)	SIPA (n = 5)
Parent Internalizing	1.00**	.800
Parent Externalizing	.400	.667
Parent Behavioral Symptoms	.316	.900*
Parent Adaptive Skills	-1.00**	.410
Youth Internalizing	.400	.200
Youth School	.800	.300
Youth Personal Adjustment	-.800	.600

* $p < .05$, **$p < .01$

Satisfaction

Both the parents and youth participants completed The Client Satisfaction Questionnaire (CSQ-8) following the nine-week intervention, in order to quantitatively evaluate their satisfaction with the intervention. Items are rated on a four-point scale and are summed together with the higher scores indicating greater satisfaction. The means for the parent and youth participants are listed below (see table 19). Overall, the means ranged per item ranged from 3.2 – 3.9 for parents and 3.44 – 3.89 for youth. Some variability was present in the parents' scores (see table 20).

Table 19

CSQ Means

Item	Parent (n = 10)	Youth (n = 9)
1: Quality of service	3.9	3.78
2: Kind of service wanted	3.4	3.78
3: Met your needs	3.2	3.67
4: Recommend program to a friend	3.7	3.89
5: Amount of help received	3.2	3.78
6: Deal effectively with problem	3.4	3.44
7: Overall satisfaction	3.6	3.78
8: Return to program again	3.7	3.67

Table 20

Parent responses to CSQ (n = 10)

	Number of responses given per level			
Item	Level 1	2	3	4
1: Quality of service	0	0	1	9
2: Kind of service wanted	1	1	1	7
3: Met your needs	0	1	6	3
4: Recommend program to a friend	0	0	3	7
5: Amount of help received	1	0	5	4
6: Deal effectively with problem	0	0	6	4
7: Overall satisfaction	0	0	4	6
8: Return to program again	0	0	3	7

Qualitative Analysis

A thematic analysis was completed of all of the parent sessions over the four cohorts. There were five primary themes that were present, which included late effects, support at home, parents' struggle for balance, managing stress, and meaning making, as well as many secondary themes (see table 21). In addition, qualitative interviews were conducted following the intervention and reviewed to determine the impact of the intervention for youth and their parents.

Table 21

Qualitative Themes in Parent Group

Primary Themes	Secondary Themes
The Late Effects of Treatment	Academic, Cognitive, and Executive Functioning School Advocacy Social Difficulties Emotional and Behavioral Functioning
Parental Support for Pediatric Survivors	Concerns about Providing Too Much Support Differing Parental Expectations and Priorities Supporting Children through Developmental Changes
Parents' Struggle for a Balanced Life	Balance with Children Spousal Relationships and Co-parenting Communication with Extended Family Employment and Financial Stress
Stress Management for Parents	The Challenge to Cope Minimizing or Avoiding Concerns Coping Strategies Mindfulness Prioritizing
How Parents Made Meaning of Their Experiences	Grief Gratitude

The Late Effects of Treatment

The most pervasive theme reflected throughout the four parent groups was the challenge for the parents to manage the late effects experienced by their children. These late effects were in a number of domains, including academic, cognitive, and executive functioning; social skills; and emotional/behavioral symptoms.

Academic, Cognitive, and Executive Functioning

The majority of parents described how their children had some deficits in their academic performance and executive functioning. These included difficulties with attention, impulsivity, organization, memory, time management, initiation, and completion of multi-step directions. For example, one participant described how her son

had difficulties with organization, stating, "he may have homework in a class, but not bring the right book home" (Cohort 2, session 2). The intensity of these late effects varied by child, but they all appeared to be impacting their academic performance to some degree.

Parents often reported that their children were learning at a slower pace than their peers. One mother noted that her 10-year-old son had been a grade behind in reading since kindergarten and while he continued to make gains, his pace was not at the same rate as his peers (Cohort 3, session 7). These gaps in learning are likely two-fold: while in treatment, many children missed a significant amount of school; in addition, the late effects of treatment may have also impacted their ability to take in novel information. While many of the parents described how their children repeated at least one grade, one mother noted that her eighth grade son missed four months of fifth grade due to treatment, but was still promoted to sixth grade the following year (Cohort 2, session 5). She wished that he had repeated fifth or sixth grade due to the gaps in his learning, which were now impacting his performance in eighth grade.

> When I talked to the principal, he said that he's going to fail the year. And for me, like you said, if he needs to fail for the year, okay, if he needs to stay in for one more time, but I don't know why they didn't do it in sixth grade… The principal said that he may need to stay another year and for me, that's fine, because I know he's behind (Cohort 2, session 5).

The same parent acknowledged her frustration with her son's change in motivation at school. She noted that he did well academically and behaviorally when he was in

elementary school before treatment, but at the time of the group, he had little motivation and was failing most of his classes.

School Advocacy

The main attributes of school advocacy were parent knowledge and persistence. When parents were knowledgeable and persistent, their children received quite a bit of school support, whereas when parents had little knowledge or were less persistent, their children were often expected by school officials to be independent. Many parents described how they were required to act as advocates for their children in order for them to receive support at school, as teachers and school administrators were often unaware of the impact of late effects following treatment. As one mother voiced, "once their hair grows back, the kids look like all the other kids" (Cohort 3, session 2). Without the visual reminder, it was easy for teachers and other school personnel to overlook the long-term impact of their treatment. Thus, the onus was often on parents to advocate for their child's academic needs.

Parents varied in their knowledge of and ability to navigate their children' school systems. Many experienced substantial struggles in their attempts to communicate their child's needs with the school. One mother, who was a native Spanish speaker, described how her limited knowledge of the English language was a significant barrier in her attempts to communicate with her son's teachers via email. Others reported that it felt manageable to communicate with one teacher, but were challenged when attempting to navigate the larger school system. One parent described the steps that she took in order for her elementary age son to receive support:

> He suffers from concentration, memory, ADD, and is behind in reading, things like that. Things don't come as easy to him as they do to other kids. That's something we struggle with, it's something that we had a real struggle with last year, we just didn't have a teacher who worked with him, so we ended up changing classes (Cohort 3, session 2).

Despite these challenges, the majority of the youth in the study received formal educational support, either through a 504 accommodation plan (72%) or an individualized education plan (IEP) through special education (18%). Only one child did not receive any support at the time of the intervention, which may have been a result of his attendance at a private school that did not have formal academic support programs. While parents often felt it was difficult to communicate their child's needs with the schools, they were generally persistent enough to be successful. For example, one parent of an eighth grade boy noted:

> This year I had a hard time getting the teachers on board. I ended up having two 504 meetings just to let them all know…and I think I have them all now, except for math. Math is the only one I'm struggling with and I don't know why (Cohort 4, session 2).

Several other parents echoed this sentiment, stating that they had to strongly advocate for their child's needs every year, as each year brought a new teacher or team of teachers. This was particularly notable around the major school changes, including the transition from elementary school to middle school and middle school to high school. One mother of an eighth grade boy noted concerns about the increased amount of homework that her

son would receive in ninth grade, as he did not have homework in middle school, and she anticipated that it would be very challenging for him. Other parents shared similar concerns about the transition from middle school to high school and worried that their children would not receive the same level of support in high school due to the increased expectations for independence.

Social Difficulties

Social difficulties was another concept discussed by many parents, which could be broken down in to impact of social isolation during treatment and resulting decrease in confidence. These difficulties appeared to be most prominent for only children, compared to survivors with siblings.

In addition to academic and executive functioning difficulties, several parents reported that their children had social problems, which they felt were related to their social isolation during treatment. For example, one mother noted that her 10-year-old son was in treatment when he was four years old and spent little time with peers that year (Cohort 3, session 3). She felt that this gap in his social development had a direct connection to his current social difficulties, as he did not have the same opportunities to develop his social skills as a preschooler. Interestingly, the majority of parents who shared these concerns had only one child. It appears that the social isolation that is typical during treatment may be exacerbated for only children, as they may have fewer social opportunities, compared to children with siblings, who would likely have some ongoing social interactions with their siblings while they were on treatment.

Several other parents described how they felt that their children were less confident socially, perhaps because they were accustomed to being around more adults than children. A mother of a 10-year-old boy noted:

> He's shy. He's very comfortable with adults, but he has a problem, no I shouldn't say problem, he's not as confident with his peers, which is bizarre because he's fine with adults… To say that he's not sociable is not true, because you'll see that he's very sociable, but with children, his peers, he actually is extremely shy. We've been working on that. When he went back to school, if no one asked to play, he would just be by himself. I think what it is, is that he doesn't comprehend the complexities of being a child. He thinks like an adult, so to him, why can't they just engage me, because adults engage you. Adults will engage children, they don't have to wait for them to come up to them, you know, but children need that push. If he would ask, they would let him play or include him, but they just assume, oh that's X, he's probably got chemo-related stuff, so he won't (play). He hasn't developed a thick skin, because he hasn't been around children. I think if he had more exposure with kids, he would have developed a thick skin… He's 10, in some ways very mature, but in some ways (less mature) (Cohort 3, session 3).

The mother of a 12-year-old boy noted a similar sentiment (comments in italic were made by a leader or another participant):

> He's a sensitive kid. Like if they have to pick partners for a project, he won't ask anyone, he's too like…I don't know if it's a self-conscious thing or… *Shy?* He's

shy, but I think it's a self-confidence thing where you don't, I don't want to make somebody be stuck with me type of thing, or… *He doesn't want people to say no?* Exactly (Cohort 2, session 6).

These comments reflect concerns from parents about how their children's confidence in social situations may be negatively impacted by their experiences in treatment.

Emotional and Behavioral Functioning

Many parent described several changes in their children's emotional and behavioral functioning as a result of treatment, which included increased emotional sensitivity and irritability as well as anxiety.

Several parents reported that their children who had gone through treatment were more emotionally sensitive or reactive than their peers or siblings. For example, one parent of a 9-year-old girl described how her daughter often became dysregulated:

X has my temper, so she'll start crying, start saying how she hates doing whatever situation she's in at that time. She'll say how she can't do it. She's really hard on herself and she'll start crying. I have to tell her how she needs to calm down (Cohort 4, session 5).

Another parent described how her son had intense separation anxiety, needing to sleep in the same bed as she and her husband and wanting to know where she was at all times, despite completing treatment several years before and generally being in good health. Several other parents described how their children had frequent worries about their parents dying. For example, two mothers of sons discussed this commonality:

> My son, he's more like his dad. He does worry, he worries about me and his father passing away, things like that. He's very sensitive. *That's a concern of his too. My husband will not get a will, he just won't do it and my son, that's one of the things that's really, really bothered him. He's like, what's going to happen to me? Where will I go?* Yeah, it seems like he worries that one of us may pass….Before he would cry and tell us, "I don't want you to die, Mommy" but now he's able to talk about it (Cohort 5, session 3).

Parents also reported that their children had significant anxiety about their school performance. This was particularly salient for the adolescents, who were more conscious of how their grades had a direct impact on their ability to play sports or be admitted to a competitive university. One mother of an adolescent stated, "I don't know what he worries about, other than his grades, because we've been so uptight about it…Grades, that's pretty much all he worries about, cause it's been a big issue" (Cohort 5, session 3).

While several parents shared that their children had anxiety post-treatment, many parents reported that their children had heightened levels of anxiety during treatment, as they attempted to cope with the impact of their treatment and reality of their mortality. One mother described how her son was overwhelmed when he lost his hair following his chemotherapy treatment and refused to get out of the car in front of the family's home (Cohort 3, session 7). Other parents described similar sentiments, particularly for children who were in elementary school or older during their treatment, as they were more aware of the circumstances and could understand the larger implications of their cancer diagnosis and treatment.

Parental Support for Pediatric Survivors

Another primary theme for all the parents was the level of support that their children needed at home. The characteristics of this theme included the quantity of time, type of assistance needed, and parental strategies used.

Every parent discussed the amount of support that their child required of them at home once they had completed treatment and transitioned back to school. Many parents discussed how their children needed significant support, particularly for activities related to attention, memory, and organization. They reported that they spent a substantial amount of time assisting their children with their homework and other household responsibilities. One parent described how her child had difficulty paying attention when she was giving her directions and needed frequent reminders to complete tasks independently. She also noted that her daughter was unable to complete multiple-step tasks independently, stating: "multi-point verbal instruction, if she gets 3 or 4 pieces of instruction, after about 2 things, she's finished" (Cohort 4, session 2). Another parent shared how her 14-year-old son needed her to sit with him and help him make flashcards for one of his classes, which included her making suggestions about what he wrote on each card (Cohort 5, session 4). These comments reflect many shared by the parents about the impact of executive functioning weaknesses on the children's functioning at home.

Parents used a variety of strategies to assist their children with these executive functioning weaknesses. Several parents described how they insisted that their children repeat back what they had just asked them to do, in attempts to help the child pay

attention to and recall the instructions. Another mother described how she wrote down a list of things to do and posted information on the fridge to remind her daughter what she needed to complete that day (Cohort 4, session 2). Being aware of and minimizing distractions was another strategy employed by at several families. Overall, the most commonly discussed strategy was consistency and routines, which many parents reported was helpful for their children in remembering and following through on their responsibilities (Cohort 2, session 7; Cohort 4, session 2).

Concerns about Providing Too Much Support

Within the larger framework of support at home, parents in each of the four cohorts questioned that amount of support that they were providing to their children. While it was clear that every parent's goal was to help their child become an independently functioning adult, there were a variety of thoughts about how to best help their child reach that goal. At times, parents reported being frustrated with the amount of support that their child required, wondering if their behavior was related to the late effects of treatment or simply temperament. As one mother of a 9-year-old girl stated:

> I don't know if it's attitude or effect (of the treatment), that's why I'm glad I'm here. She'll look at me straight while I'm telling her and it will go in one ear and out the other. I have to constantly repeat myself. I think it's because she doesn't care, but she'll come back to it and do it later (Cohort 4, session 2).

Other parents reported similar thoughts, concerned that if they gave their children too much help, they would grow to expect that others would always provide for them. As one mother put it, "I don't want him to use cancer as a crutch" (Cohort 3, session 2). In

the same way, another parent reported that she didn't want her child to "live in a bubble" and be unaware of real world expectations and responsibilities (Cohort 3, session 4). One mother described a situation in which her child got in trouble at school for reading a book. She noted how her initial reaction was to protect him, followed by the realization that it was important for him to receive the natural consequences from his teacher of breaking the school rules.

> So far, what's he's experienced is that if someone has treated him unfairly, I stand up for him. I go and sort it out. But this was a good opportunity for him to realize that I'm not always going to back you up. If you've done something wrong, you've got to own up to it. I t's a bit of a hard lesson (Cohort 3, session 4).

Differing Parental Expectations and Priorities

Similar to the question of how much support to provide, parents wondered whether their expectations for their children who received treatment should be the same or different from their developmental peers, both for current behavior as well as long-term goals. Parents often spoke of the balance of wanting to do everything possible to help their child, while at the same time, being mindful of the impact of late effects and how their child might have long-term consequences that are challenging to remediate. One way that this played out differently between parents was the amount of extra academic tutoring children participated in versus participation in other extracurricular activities, most commonly sports. Several parents described how their children participated in formalized tutoring programs after school, on the weekends, and over the summer and had little time for other activities. Many of these families seemed to have

the view that their children needed to have every opportunity to make up any lost academic ground in order to keep up in the "real world."

On the other side, several families appeared to be mindful of the late effects that were impacting their child's academic and cognitive functioning, but also wanted their children to be well-rounded and participate in activities that brought the child happiness. For example, one mother of an elementary school aged-boy had planned for him to participate in a traditional outdoor camp for the majority of the summer, with a little time spent on academic activities, as opposed to having him attend a more rigorous academic summer program. It appeared that she felt that her son needed a break from his academics in order to regroup after exerting a significant effort throughout the school year.

One mother of a 12-year-old boy with significant academic difficulties and loved sports, described the challenge of balancing her son's academics and sports schedule:

> I can't take the sports away from X, because that's too important to him, that's his release, that's his love. You have to have something you love and enjoy doing. So, even for me, when I say, you're not going to be able to go to practice if you don't get this done, in the back of my mind, I'm thinking, I'm still going to let him go (Cohort 2, session 4).

Other parents also brought up the importance of school clubs and activities in order for their adolescents to get into an academically demanding college (Cohort 5, session 4; session 5). Overall, this theme of balance between wanting to prepare children for the future, but also giving them time to "just be kids" was pervasive in all four groups.

Supporting Children through Developmental Changes

Another concern that was expressed by several parents was the challenge of managing their children's transition into adolescence and the accompanying behavioral changes, which included greater demands for control and independence. Several mothers noted that their adolescent sons had become more private and were sharing less information with them (Cohort 5, session 4). Parents described how adolescents were also starting to have more preferences about their activities and the time spent on academics versus other extracurricular activities. Parents voiced the challenge of wanting to give their children some amount of control, but also having their own preferences about their activities (e.g. youth spending more time on homework or studying for tests vs. playing video games or going out with friends). While this balance is quite typical for parents of adolescents, this debate was exacerbated for these families based on the fact that the adolescents had undergone treatment and were likely experiencing late effects. Parents described how their adolescents wanted to be "normal" and did not want to think about the impact of their treatment, particularly if it occurred when they were quite young. One mother of an adolescent boy stated:

> He doesn't remember much, he only remembers the positive things from it, which blows my mind. And I have to remind him sometimes of the difficult stuff. Like, I have to say, "we're here because…" And he's like, "Mom, why are we doing this? Because I'm fine." And I go, "you are fine, but we're going to help you be finer. Because you are doing really well, but there are some things that you need some help with and you don't want to hear it from me anymore. And I'm

> frustrated and you're frustrated, we're both really frustrated with one another and it's affecting our relationship". It's all those executive functioning, attention challenges (Cohort 5, session 2).

Similarly, this transition to adolescence may be particularly challenging for parents of children who underwent cancer treatment, as the parents were accustomed to having an active role in their child's life, likely more than typically-developing children. One mother of several adolescents, including one who had undergone treatment for cancer, discussed how she missed when her children were younger and needed her more (comments in italic were made by another group member):

> I am working and I feel that I am not taking care of them. And I say to them, 'I am working and I don't feel like I'm taking care of the house and all the stuff' and my daughter says to me, 'mom, we don't need you anymore.' *What?* No, it's not that we don't need you, but we're in school the time that you're at work. *It's a good thing.* Yes, but I think for me, it's a different feeling (cohort 5, session 6).

Her comments reflect the contrasting feelings experienced by parents: grief about how children are becoming more independent and not needing them as much, coupled with relief that they are more self-sufficient. While this bittersweet experience is not unique to parents of cancer survivors, it may be heightened for them given the level of support that they once provided to their children.

Parents' Struggle for a Balanced Life

Nearly every group session over the four cohorts included some discussion of the parents' attempts to balance the various aspects of their lives, including their relationships with their children, spouses, extended family members, and coworkers.

Balance with Children

Balance was children was defined by the time spent with children at home, the parent's relationships with their other children, and differing expectations for siblings. The majority of the parents in this study had more than one child at home (83%) and half of them had at least three children. Thus, parents spent a great deal of time not only parenting their child who was a cancer survivor, but also other children. Several parents spoke about the challenge of providing support to their child who was a survivor, but also their other child/children. One mother of two middle school aged sons, reported that there was more distance between her older non-survivor son and herself. "My other son, his education suffered quite a bit because of him, because of what we were going through, we could not focus on him (the child in treatment)…there is so much distance between me and my other son, that's really hard" (Cohort 3, session 4).

Parents shared concerns about having different expectations for different siblings. One mother questioned herself, when one of her other children reported having academic difficulty in school. She noted that she initially dismissed her child's concerns, but then wondered, "if it were X having trouble in school, would I be doing something different?" (Cohort 4, session 7). Other parents reported that they were less concerned about having different expectations for their child, stating "different people need different stuff"

(Cohort 4, session 2). Another parent shared how her son initially required more support after he completed treatment, but described how, at that time, her daughter needed more adult attention at home with a recent transition to high school and her own learning disabilities (Cohort 4, session 7).

Spousal Relationships and Co-parenting

Within the overarching theme of struggle for balance, spousal relationships were impacted by time constraints, disagreements about parenting, and having few emotional outlets. The majority of parents who participated were married or engaged to be married (80%) and many of them spoke described the challenge of having time to spend with their partners. Often the time that they did have with their partners was spent trying to figure out how best to parent their children. At times, parents described how they disagreed with their spouses in how to care for their child who was a survivor. One mother reported that she and her husband often had different views on their 12-year-old son:

> X needs that down time after being in school all day. My husband doesn't get that at all…He had like a two hour conversation with X last night…and then after talking with him, he said, "he's dealing with a lot of stuff" and I was like, no kidding. He doesn't understand that he's working really hard (Cohort 2, session 7).

Another parent reported that she felt like she was the stricter parent, as her husband felt that it was satisfactory for their son to play video games after dinner, whereas she wanted him to be doing homework (Cohort 3, session 4). In addition, several parents spoke

about taking their frustration out on their partners (Cohort 4, session 5) or not feeling emotional supported by their spouses (Cohort 2, session 3). It was clear that parenting a child who is a cancer survivor is very stressful and may have a negative impact on the parents' relationship.

Communication with Extended Family

While many parents described how they relied on extended family members for emotional support, particularly during their child's treatment, some mentioned challenges in communicating with family members about their child's treatment and adjustment after remission. One mother, who lived with her parents as well as her three children, reported that she had significant difficulty with her own parents' interactions with her son, who was a survivor, as they treated him differently from his siblings (Cohort 4, session 2). She noted that they expected him to do less for himself and would often intervene when she was setting limits for her son. She discussed how it was necessary for her to speak directly with them about her expectations for her son's behavior, which was quite challenging for her, since she was living in their home. Another mother reported that she felt relieved when her extended family went home, as it was challenging to hear their worries and comments about her son's health:

> (It was helpful that) my family came from my country, but on the other hand, when they left, we felt more relieved, because we could make our own decisions. Because you know, they would say, "he's kind of yellow. You should tell the doctor. He's too thin. He's not hungry." And finally, all the anxiety, start to

> invade your brain and you cannot focus on your kids. And when they left, I thought, we can do what we want to (Cohort 5, session 3).

Employment and Financial Stress

The challenge of balancing employment with parenting and related childcare was another prevalent theme. Several parents described the difficulty that they had in being emotionally present at work, as well as negotiating changing work demands. One mother described the challenge of returning to work as a teacher after her child completed treatment.

> How can I love other kids that much? How can I care about other children that much? It was really hard for me. We were fresh out of treatment, they were so fortunate, they have no idea what adversity is…it was really hard going back to work. I would just go home and cry forever. How can I love all these other kids as much as I love my own? It takes a long time and I'm still getting there (Cohort 4, session 6).

Another parent described how her work environment was not supportive of her needs parenting a child with cancer. She explained how her job of twelve years was threatened when she had a new boss who was not willing to be flexible with her work hours:

> I've been there twelve years and this is what I get after twelve years? …I can go look for another job, but I have to manage everything, with everything that is going on with X. I'm being dedicated. I'm dealing with a sick child and being with him in the hospital and still at the same time, working (Cohort 3, session 6).

Many parents also discussed financial stress, particularly around children going to college, and the juggling act of working and trying to emotionally support her children. One mother stated, "I know I'm not doing all the things I need to do, because I'm working a job and a half. I'm working too much, worrying about the future…My daughter's going to college and we don't have any money (Cohort 5, session 3). Finally, at least one mother described how she had to stop working in order to care for her child when he was diagnosed. The challenge of maintaining employment while caring for a child on treatment or in remission was described by many of the participants.

Stress Management for Parents

Given the numerous demands on them, it was not surprising that many parents reported having a high level of stress associated with caring for their children who were cancer survivors. Many of the parents reported that these experiences took a significant toll on them emotionally and continued to be a source of significant distress. They had a variety of strategies that they used to manage their stress, which varied in their utility, including minimizing concerns, active coping strategies, mindfulness, and prioritizing.

The Challenge to Cope

Some parents reported having few coping strategies to draw upon to manage their distress or taking out their frustration on others. One mother described how she was constantly in a cycle of working and taking care of her children, with little time or energy to do social activities or hobbies.

> Being social, I don't have the energy to be social, I know that makes people happy and it's important, and I know it feels good to be social, but I don't care.

> Cause I'm tired and it's that cycle, you know, when I get home at 8 o'clock at night, Facebook is as social as it gets, and that's really not being social (Cohort 5, session 3).

Others reported that they had difficulty managing their distress in productive ways, and found themselves taking out their frustration and stress on their children and spouses. One mother described how she felt that she had little time to visit with her children and felt that she was yelling at them all the time (Cohort 4, session 7). The challenge of coping with this stress was a common theme across the four cohorts.

Minimizing or Avoiding Concerns

One way that parents managed the stress was by minimizing their concerns or trying not to think about their challenges. One mother described how she tried to be calm on the outside, but reported that she had significant worry inside, even if she did not share it with anyone. She said, "I sound positive, but I'm not positive. Everything is okay, fine; on the inside, 'I'm going to die'" (Cohort 5, session 3). Two mothers described how they attempted to avoid thinking about their child's diagnosis, treatment, and related late effects:

> I know that it's one of the side effects, but I don't want to connect that. *It's like you don't want to give it any weight because if you give it weight, it might make it worse.* Not that I want to forget it…*But you want to move on. You don't want to get stuck in it.* We talk all the time, well, he had cancer at the age of three, but I don't want to think about it (Cohort 5, session 5).

For the parents that discussed the use of this strategy to manage their stress, it seemed that thinking about the experiences that their child had been through and the related late effects was simply too overwhelming, which led them to choose not to think about it at all.

Coping Strategies

While many parents acknowledged stress and difficult times, they also discussed many coping strategies that they used to manage their current situations. These included faith and spirituality, reliance on friends and family members, humor, and exercise.

Many families spoke of coping with the everyday challenges through their faith and spirituality. One mother said, "when I go to church, it seems like everything he talks about, is what we have done that week. I t's really just amazing. Sometimes, that really, really helps" (Cohort 5, session 3). Thinking back to when her child was in the ICU, another parent reflected, "God healed X through the doctors and he will be fine" (Cohort 3, session 5). Another described how spending time in nature helped to quiet her mind. Finally, a mother of an adolescent boy spoke how horseback riding helped her to align her mind and body and meditate (Cohort 5, session 3).

Other parents described how spending time with their families, by playing games or having dinner together brought them joy and helped them cope. Several parents also discussed the use of humor or a positive attitude in order to avoid feeling pitiful. "Every chemotherapy (session), I wore new clothes, because I thought, 'I'm not going to feel sorry for me or my kid.' So I was always in my lipstick, with my high heels" (Cohort 5,

session 3). Finally, several parents discussed how working out or being active helped them to relax.

Mindfulness

The concept of mindfulness, or being fully attentive to the present, was consistent with several comments made by parents to describe how they coped with stress. While few parents used this word explicitly, many parents reported trying to be in the present, the common notion of "living one day at a time" and not being overwhelmed by worries about the future. One mother of a 10-year-old boy was fond of euphemisms and often used them to relay her thoughts on how she managed her worries. She shared how it was helpful for her to remind herself "this is a journey, not a sprint," which encouraged her to take it little by little and not get overwhelmed (Cohort 3, session 5). She also stated, "let the cards fall where they may" as she felt it was easier to acknowledge some events and move on, rather than fighting or questioning why they occurred (session 2).

Several parents discussed how they found it somewhat easier to be focused on the present while their child was on treatment. One mother stated:

> I didn't worry as much when he was sick, as I worry now. I didn't have time to worry. You were just in the moment, you had to live in the moment, and I learned to live in the moment. I think that's what helped me cope. And I made plans, that helped cope too, I think making plans helps. We talked about what he wanted to be when he grew up (Cohort 5, session 3).

This focus on mindfulness was shared by several other parents in the other two cohorts as well.

Prioritizing

One way of managing stress that was discussed by many parents was the importance of prioritizing and not becoming distressed by the small tasks that you were not able to complete. As one mother put it, "Nothing at home or at work is as big of a deal as your child having cancer, so you prioritize and get it done" (Cohort 4, session 5). This quote from the mother of a nine-year-old girl was consistent with the messages shared by other parents who reported that they did not have enough time to complete all their daily tasks, which required them to make difficult choices about what tasks were completed and what were left for the following day. Another mother said it this way, "To carry the burden of everything becomes too heavy, so you have to let something go" (Cohort 3, session 5).

Discussions between parents in the third cohort exemplified the various ways that parents cope with stress. In the first few sessions of that cohort, it was clear that two of the parents had divergent perspectives on they managed their children's treatment, but this difference became even more apparent in the second half of the group, following the relapse of a third participant and his discontinuation of the group. Learning about the relapse and the many challenges associated with it seemed to bring back many memories for the two remaining parents of their own child's diagnosis and treatment and highlighted their contrasting perspectives. For example, one mother reflected back on her son's experience in the ICU when he nearly died, and shared how she felt that God saved her son (Cohort 5, session 5). She noted that her faith kept her from worrying about a possible relapse and that she was thankful to have this comfort. The other mother

described how she continued to struggle with her son's treatment and had intense amounts of anxiety that were difficult for her to manage. She described how she asked her son the same question about his pain over and over again, as she was so worried about him relapsing (Cohort 3, sessions 1 and 7). These differing perspectives highlight the wide range of parent responses to significant distress.

How Parents Made Meaning of Their Experiences

While each family had their own story of their child's diagnosis, treatment, and recovery, there were certain similarities between their perspectives as they reflected on their child's experiences with cancer and how they made meaning of it. While a few parents shared that they found it easier not to think about their child's experiences, the majority of participants shared some about how they understood and conceptualized their past and present journey. The overall responses could be split into two viewpoints, those who endured grief and those who experienced gratitude.

Grief

While the majority of the parents described some amount of grief and feeling of anxiety associated with their child's diagnosis of cancer, several of them voiced continued feelings of grief and sadness over their child's experiences even after they had completed treatment. These parents acknowledged how they wished that events had occurred differently and their children had not been diagnosed with and treated for cancer. One mother wondered,

> Where would he be if he hadn't had cancer? I just wish all of a sudden, his brain would be perfect again. It just gets harder, every year, it's just going to get

> harder, worse and worse, the farther you are from treatment and the more complex things get (Cohort 2, session 7).

This sentiment seemed to be particularly salient for youth who were diagnosed and treated later in their childhood, as parents had a glimpse of their time as a "typical" child before they underwent their treatment, and were often painfully aware of the differences in functioning pre and post treatment.

Gratitude

While all the parents described having significant stress, several also acknowledged feeling grateful for what they saw as positive aspects of their current situation or insights that their family's situation could be worse. One mother of a 10-year-old boy shared,

> I feel grateful. I look around and I see people who have it so much harder than I have it and I really genuinely believe that. Maybe it's kind of a bad thing, but I almost feel bad, feel guilty to complain because, you know, when I'm at the hospital and I've seen some of the families there and I understand that everyone has struggles. And their struggles are worse than mine. So I feel this intense gratefulness (Cohort 3, session 1).

Another parent shared that she felt relieved that her child was diagnosed at age two, "(It was) better than any other time. We wouldn't have wanted it before two or we didn't want it after ten" (Cohort 5, session 2). A parent of an adolescent boy who was diagnosed at age ten, shared that she felt that it was a blessing that her son had a mature perspective and coping skills to deal with treatment (Cohort 3, session 7). Other

participants described how the experience of their child's diagnosis and treatment brought the family members closer together (Cohort 5, session 3). One mother described how the situation reinforced the message to her that she and her husband could fully trust and depend on one another and were their own family. In summary, several group members described how they felt some aspect of gratitude associated with their child's cancer diagnosis and treatment.

Parental and Youth Views of the Intervention

While a few parents discussed the impact of the intervention within the last few group sessions, the majority of the data about parental and youth perspective of the intervention was gathered through the qualitative interviews that were conducted approximately one to two weeks after the completion of the intervention. Several components of the intervention were described as helpful, which included the psychoeducation that was provided to the youth and shared with the parents, the parent-specific psychoeducation that was provided (based on group preferences), and the impact of participating in a group intervention with others who had gone through similar experiences.

Child Psychoeducation

Both parents and children described how they felt that the specific skills that the children learned in their group were helpful and were somewhat generalizable to home and school. The skills that appeared to be most memorable and useful were the strategies to manage attention (e.g. body check and 'Boomerang it back') and the coping strategies.

For example, a ten-year-old boy noted that "I used Boomerang it Back some at school. I'd be staring off in space, notice, and then Boomerang it Back." Similarly, a twelve-year-old boy noted that "doing the body check really helped me in school and in class, and in my special activities. Like, I would pay attention again and I would catch everything they're trying to tell us, in case it's important." Finally, another twelve-year-old boy described how coping helped him at school (questions in parenthesis were made by the interviewer),

> I kind of did relax at school. You don't know how much stress happens after I get partnered up with a partner I didn't really like and then, find out, aww man, I got a bad grade on this. (*What coping skill did you use?)* I did deep breathing. (*Did it work?*). Yeah, it did.

Parents described how their children were able to apply the skills that they learned in group to their home and school environments. One mother of a twelve-year-old boy described the changes that she noted, "His focus got better for sure." The mother of a nine-year-old girl shared, "she learned how to manage stress. She tends to act out when she can't do things as well as her peers, but she has been using the stress box to cope with stress." However, several parents noted that they were unsure if their children were consistently applying the skills at school, since they were not present to observe them.

Parent Psychoeducation

Parents also described the skills that they learned in the parent group and how helpful those were in their interactions with their children and spouses. Many of the parents described how they had become more active listeners when their children were

speaking to them and they noticed that their children seemed to enjoy having their undivided attention. One mother noted how she was able to use the skills both with her son who was a survivor as well as her daughter who had not undergone treatment, but had her own learning disabilities. She noted,

> I think it's kind of helped me slow down and listen to their feelings or why they're upset versus just saying, oh 'I don't have time right now' or 'get over it' or you know…so it's made me aware, I guess. More aware than I was before. (*And how has this impacted your relationship with X?*) Anytime I do something like this or therapy with Dr. X, it brings us closer and I feel like we're really communicating.

Other parents had similar thoughts, including one mother of a 12-year-old boy who reported that, "I'm calmer now in handling things." Overall, it appeared that the majority of parents felt that the psychoeducation component of the group was useful.

Group Membership

Both the youth and parents reported that they enjoyed meeting peers who were in similar circumstances. One boy described how he liked "making new friends" and another mentioned how he enjoyed "meeting other people." However, the youth participants of the four cohorts examined in this study rarely spoke in their exit interviews about feeling connected to the other group members based on their commonalities and ability to relate to one another. This is in contrast to the pilot group, in which many youth participants described this phenomenon, as well as other qualitative studies that have described this being a common theme (Cassano et al., 2008). This is not

to say that the group members did not appear to enjoy spending time with one another; it is simply notable that this was not expressed so directly as in previous studies.

Most parents, on the other hand, described openly how they felt it was beneficial to meet with the other group members and discuss their experiences parenting a child who was a cancer survivor. One mother described her experience, "It was very interesting because a lot of us had the same things happen to our children. That was really helpful, to know that there are other people out there dealing with the same thing." Another mother noted that she had not participated in any parent support groups in the past, but after this experience, wished that she had sought them out in the past. She noted,

> I was amazed at seeing and hearing other stories from other parents and knowing that they went through the same thing that I did as well. It was interesting to interact with them and talk to them and get feedback and hear different stories. It was just really interesting.

It appears that for many parents, this was the first time that they met several other parents who had similar experiences as them and many of them felt that this opportunity was very helpful in helping them to feel understood.

Exceptions

However, at least one child and one parent described how they did not feel fully connected to the group and this appeared to have a significant impact of their overall perspective of the intervention. One of the boys who participated in the third cohort was still on maintenance treatment and he described how it was challenging for him to be on

the only group member who was still on treatment. He noted, "I noticed that I was only one still on treatment. It would have been more comfortable if someone else was on treatment, since I didn't have hair and had to wear a hat." While he reported that he felt that he benefitted from learning the skills in the group, it appeared that he did not receive the additional benefits of feeling connected to and understood by others that the other group members described.

One parent who participated in the fifth cohort described how she felt that she did not have the same perspective as the other parents,

> I felt like they were on the same page and I was on the other page. They had the same type of problems and I don't have them. I had different types of problems. They were more stressed…they were more overwhelmed and for me, it was a long time ago and I already cry and I already asked why and I think I'm in a different stage now.

Similar to the youth participant, this mother reported that she felt that the intervention was helpful to her son, but she did not receive the same interpersonal benefits from being a member of group where you are understood and accepted by others.

Summary

In conclusion, parent and youth participated in exit interviews in order to learn more about their perspectives on the two components of the intervention, the youth group and the parent group. One major theme was the benefits of psychoeducation for both the children as well as parents. Secondly, many of the participants described the positive relationships that were formed within the various cohorts. While there were several

exceptions to these themes, including a few group members who felt somewhat disconnected to the groups, overall analysis indicated that the participants felt that the intervention was helpful and they enjoyed the opportunity to interact with others who had similar previous experiences.

Triangulation

The concurrent triangulation approach was used to triangulate the data from the quantitative and qualitative analyses. The data set was transformed based on Onwuegbuzie and Teddlie's (2003) seven-step model (Johnson & Onwuegbuzie, 2004). The results of the quantitative data were rewritten in a narrative format to compare to the qualitative data. The data was then compared directly and consistencies and differences were discussed. For example, in the evaluation of the participants' psychological functioning, the results of the BASC-2 were described and compared to the qualitative themes present in the parent group and the post-intervention interviews with the youth and parents. Similarly, for participants' executive functioning, the results of the BRIEF were compared to the qualitative themes in the group and post-intervention interviews. Parental stress was analyzed by comparing the narrative description of the PSI/SIPA results to the qualitative themes in the group and post-intervention interviews. The relationship between parental stress and youth psychological functioning was evaluated by considering the implications of the correlations of the two measures to the qualitative themes. Finally, satisfaction was determined by comparing the CSQ descriptions to the qualitative post-intervention interviews. The results of these comparisons will be presented in the discussion in order to answer the final overarching question: are the

measures of psychological and executive functioning in the quantitative component consistent with the themes present in the qualitative data?

Chapter 5: Discussion

This chapter brings together the quantitative and qualitative results and discusses the implications of the findings in light of the research questions. Previous research has shown that pediatric oncology survivors often experience late effects in their cognitive, academic, executive, and psychological functioning subsequent to their chemotherapy and radiation treatment (Winick, 2011). Several interventions have been developed which use cognitive remediation to improve executive functioning (EF) skills in child and adolescent oncology survivors. While these programs have led to improvements in EF skills, they are often difficult to replicate due to the extensive time requirement. Many survivors also experience distress and elevated levels of anxiety and would likely benefit from cognitive behavioral therapy, which has been shown to be an effective intervention for children with internalizing disorders.

At this time, no intervention has been developed that would combine a short-term cognitive remediation and cognitive behavioral therapy group for pediatric oncology survivors and their parents. Therefore, the purpose of this study was to evaluate the impact of this intervention on pre/post measures of executive functioning, psychological functioning, and parental stress, while also evaluating the results qualitatively by examining themes present in the parent group as well as the post-intervention interviews with participating youth and their parents. This discussion section will review the quantitative and qualitative data and triangulate both data sources to determine if they are consistent. Lastly, limitations, implications, and recommendations for further areas of research will also be presented.

Integration of Qualitative and Quantitative Results

Psychological Functioning

Youth psychological functioning was measured by parent and youth self-report, using the BASC-2 clinical and adaptive scales. Clinical scales included Parent Externalizing Problems, Parent Behavioral Symptoms, Youth School Problems, and Parent and Youth Internalizing Problems. Adaptive scales included Parent Adaptive Skills and Youth Personal Adjustment.

Pre-Intervention

As described in the previous chapter, it was hypothesized that the psychological functioning of the participating youth would be greater than the mean for the clinical functioning and below the mean for adaptive functioning before the intervention. The results indicated that this hypothesis was partially true. In comparing the pre-intervention scores to the 90% confidence interval, approximately two-thirds of parents noted that children had lower adaptive skills than their peers, which was comprised of the following components: adaptability, social skills, leadership, study skills, functional communication, and activities of daily living. Similarly, nearly half of parents indicated that their children had more behavioral problems than their peers, which included attention problems, withdrawal, and atypical behavior. Less than a third of the parents thought that their children had more difficulties with internalizing or externalizing problems than their peers. Likewise, very few youth rated themselves as higher than their peers on internalizing problems, school problems, or personal adjustment. When these pre-intervention scores were analyzed using the BASC-2 qualitative ranges, the majority

of scores did not fall in the "at risk" or "clinically significant" ranges. Contrary to the previous comparison, only one-third of the parent-rated adaptive skills of youth were scored as more problematic than the normative sample.

These findings are fairly consistent with both the literature on pediatric oncology and the qualitative themes that were present within the parent intervention. Studies have shown that some pediatric oncology survivors may be more withdrawn than their peers and can experience social skill difficulties, which may be related to the social isolation that they experienced when they were in treatment and continue to experience due to feeling different from same-age peers (Askins & Moore, 2008). However, not all survivors experience these social difficulties, as indicated by the varying results. This range of social experience is consistent with the qualitative themes, as some parents noted that their children had social difficulties, most commonly children who did not have siblings, while other parents reported that their children were generally doing well socially.

Similarly, difficulties with attention and study skills may reflect the impact of late effects on executive functioning (Winick, 2011). While nearly all parents discussed that their children had some executive functioning weakness, the intensity of these deficits ranged greatly as some parents needed to provide a significant amount of support for their children, while others required little support.

Given the amount of research on lasting psychological difficulties (Askins & Moore, 2008; Kamibeppu et al., 2010; Li, Chung, & Chiu, 2010), it was surprising that the parent and youth ratings did not indicate a greater level of concern about anxious,

depressive, or irritable symptoms in the youth participants compared to healthy peers. This was in contrast to themes present in the parent group, in which many parents noted that their children had high levels of anxiety, with worries about their parents dying or their school performance.

It may be useful to think about the impact of psychological late effects on a continuum, given the range of results that were found. While some children, especially those predisposed to anxiety or depression, may experience high levels of psychological responses following treatment, others may have an initial period of heightened worry or feeling down, but may return to their emotional baseline over time. It is also possible that the amount of time since treatment, as well as the child's age at treatment, may have an impact on psychological functioning. For many youth in the study, they were diagnosed at two or three years of age and completed treatment by age five or six, thus they may have had fewer memories of their diagnosis and treatment. In comparison, a few participants were older children when they were diagnosed and likely had more vivid memories of their life premorbidly and were keenly aware of the ongoing impact in their everyday functioning. This latter group may be more likely to experience grief and associated depression and anxiety than youth who had fewer memories of their premorbid lives.

Post-Intervention

Following the group intervention, it was hypothesized that the psychological functioning of the participating youth would have improved, using both self-report and parent reports. Significant differences in psychological functioning were found for parent

report of youth internalizing symptoms and adaptive skills. Additionally, youth self-report of internalizing symptoms showed significant differences. Following the intervention, both parents and youth indicated that youth had fewer internalizing symptoms. In addition, parents also noted that youth had more adaptive skills. The mean differences in all three cases were relatively small and the changes generally did not reflect a change in clinical significance, as the majority of pre-intervention scores were in the typical range. However, this data suggests that the intervention may have led to youth having fewer anxious and depressive symptoms and more adaptive functioning.

In order to determine if there were any qualitative differences between the youth psychological functioning before and after the intervention, the scores were compared using the BASC-2 qualitative ranges. While the majority of the scales showed little change, there were minor changes noted for a few scales. For example, several parents who rated their children's externalizing problems as initially problematic, based on qualitative ranges, reported that their behavior was in the typical range after the intervention. Similarly, these changes were noted by a few parents for one other scale, youth behavioral symptoms. Finally, consistent with the quantitative analysis, a few youth who initially noted concerns about their internalizing problems reported no concerns about them after the intervention. While these analyses were informal and based on qualitative ranges, they provide additional information about the impact of the intervention.

Another source of qualitative data was the interviews that were conducted with the youth and their parents after the intervention was completed. Youth were

overwhelmingly positive about the intervention and all reported that they enjoyed some aspect of the group. They described how they learned various coping strategies, including diaphragmatic breathing, relaxation, distraction, participation in activities that used energy, and the benefits of social relationships. However, it was difficult for the youth to report the frequency by which they were able to generalize the skills to their home and school environments.

Parents also reported that their children enjoyed participating in the group. Many parents noted that they had observed their children using the coping skills at home and described how the children had increased confidence, were more agreeable and less defiant, and communicating more effectively. It was often challenging for them to comment on changes at school, unless they had received direct feedback from their child's teacher.

Overall, it appears that the intervention had a positive impact on the youth's psychological functioning, specifically internalizing symptoms (as measured by youth and parents) and adaptive behavior (as measured by parents). These conclusions were consistent across both the quantitative and qualitative data. While analysis of the qualitative components indicated that youth and parents all reported that the youth learned coping skills, it was challenging to evaluate how well the youth were able to generalize the skills to school and other settings. This is a common challenge to both individual psychotherapy and therapeutic groups: while participants often learn many skills and are typically able to demonstrate them in session, it is difficult to consistently apply those skills in other, more naturalistic, settings. It appears that having parents

familiar with the content provided in the group assisted the youth in generalizing the skills at home, as parents were mindful of the skills and could encourage their children to use them at appropriate times.

Executive Functioning

Youth executive functioning was measured by parent, teacher, and youth self-report, using the BRIEF scales. The BRIEF is comprised of two broad indexes, Metacognition and Behavioral Regulation, as well as an overall Global Executive Composite (GEC) score. The Metacognition index included Initiate, Working Memory, Plan/Organize, Organization of Materials, and Monitor; the Behavioral Regulation index included Inhibit, Shift, and Emotional Control; and GEC was drawn from all the eight subscales.

Pre-Intervention

It was hypothesized that the participating youth would have deficits in their executive functioning in the pre-intervention assessment, as measured by scores above the mean for self, parent, and teacher reports on the BRIEF. When comparing the pre-intervention scores to the 90% confidence interval, at least two-thirds of the parents reported that their children had more problems in metacognition, behavioral regulation, and overall executive functioning than their same-age peers. Similarly, over eighty percent of teachers reported that the youth participants had more problems in metacognition and overall executive functioning than their peers. However, less than one-third of youth noted concerns in any of these areas. Thus, it appears that parents and

teachers were more likely than youth to indicate that the youth had significant difficulty with executive functioning skills.

When these pre-intervention scores were analyzed using the BRIEF qualitative range, over half of parents and teachers rated youth metacognition as more problematic than the normative sample. Similarly, one-third of parents and teachers rated overall executive functioning as concerning. Consistent with the previous comparison, very few youth noted concerns about their executive functioning.

Taken together, parents and teachers consistently reported concerns about youth metacognition, while youth did not report similar concerns for this area of functioning. This finding is consistent with the research literature as well as themes present in the parent group. Based on the measure used, metacognition refers to the ability to initiate, plan and organize, monitor, organize materials, and have effective working memory. Numerous studies have noted the impact of late effects on executive functioning skills, including several of the skills found within the larger category of metacognition (Campbell et al., 2007; Winick, 2011). Working memory, for example, has been highlighted by several studies as an area that has been significantly impacted by oncology treatment (Butler & Mulhern, 2005; Winick, 2011). These findings are consistent with the themes in the parent group, as nearly all parents noted some concerns about their child's executive functioning skills. The areas that were described as needing the most support included organization and working memory.

Post-Intervention

Following the group intervention, it was hypothesized that the executive functioning of the participating youth would have improved as measured by the BRIEF self, parent, and teacher reports. Repeated measures t-tests were used to compare pre- and post-intervention BRIEF scores gathered from self, parent, and teacher reports to determine if the differences were statistically significant. Significant differences were found for all three parent BRIEF scales, Behavioral Regulation, Metacognition, and GEC. While the mean differences in all three cases were very small, the data suggests that following the intervention, parents reported that youth had fewer problems with their executive functioning.

In order to evaluate the change between pre and post-intervention executive functioning, the post-intervention scores were analyzed using the BRIEF qualitative ranges in order to determine if any scores changed from the clinically significant range to the normal range. While the majority of the scales had little change, one exception was the parent GEC scale, which was initially in the clinically significant range for nearly fifty percent of the raters, but after the intervention, less than a third of the scales continued to be in the clinically significant range. Overall, it appears that parent data is most sensitive to change following the intervention.

In the post-intervention interviews, the youth described how they learned many strategies to assist them with their attention, memory, and cognitive flexibility. The strategies for attention, including 'body check' (in which the participants review several body parts to determine if they are paying attention) and 'boomerang it back' (refocusing

attention back after noticing that you were distracted) were the skills that were most commonly mentioned by the youth. Many children discussed how they used one or two of these skills at school, which assisted them to be more attentive. Parents also reported that they noticed their children using the attention strategies quite often. At least one parent noted that a teacher shared with her that she had noticed her child paying more attention in class. Similar to the previous discussion about the challenge of generalizing coping skills, it appears that it was also challenging for the youth to apply the attention strategies and other skills to school consistently. However, based on youth and parent report, it appears that the many participants were able to recall the strategies and use them occasionally at home and school.

Parental Stress

Parental stress was measured using the Parental Stress Index for parents whose children were eleven years old and younger and the Stress Index for Parenting Adolescents for parents who children were twelve years old or older. For both measures, the overall rating of stress was the primary score used.

Pre-Intervention

It was hypothesized that parental stress levels for the parent participants would be above the mean in the pre-intervention assessment. Overall, the parents' total stress scores were considered within normal limits. Thus, it appears that parents in the study had approximately the same level of stress as other parents, at least at the time that the measures were completed. This data is in direct contrast to the research literature as well as themes in the parent group. Several studies have described the intense level of stress

that parents of cancer patients and survivors have, given the increase in the demands on their role as parents (Bayat, Erdem, & Kuzucu, 2008). This is consistent with comments made within the parent group, as the majority of parents described being under a significant amount of stress given their many roles within their families. Parents described how they felt challenged to manage their relationships with their children, spouses, extended family members, and work employer and colleagues. During a discussion of stress management, several parents noted that they had limited strategies to manage their distress and highlighted that it had an impact of their ability to parent their children. Overall, while parents did not report high levels of distress through the quantitative measures, the qualitative analysis of the sessions told a different story.

Post-Intervention

Following the group intervention, it was hypothesized that the parental stress of the participating parents would have decreased. Repeated measures t-tests were used to compare pre- and post-intervention parental stress to determine if there was a significant difference. Significant difference in parental stress was found for both the PSI and the SIPA. Thus, parents indicated that they felt less stressed following the intervention.

When the qualitative data was considered, the data was consistent with the quantitative results, that the majority of parents felt that they were less distressed. Many parents described how they enjoyed speaking with other parents who had similar experiences and felt that it was helpful to have that level of support. This is consistent with the literature which states that support groups can provide parents an outlet for expressing their distress and feel supported (Bragadottir, 2008). Parents also noted how

they enjoyed the discussion on coping skills and the importance of using them to manage their own worries and concerns. Overall, the majority of parents reported that they felt that the support group was beneficial to them, particularly in the area of learning skills and feeling supported.

Parental Stress and Youth Psychological Functioning

Parental stress was measured using the PSI and SIPA and youth psychological functioning was measured using the BASC-2.

Pre-Intervention

It was hypothesized that there was an inverse relationship between parental stress and youth psychological functioning. A correlation was calculated to evaluate the relationship between parental stress and youth psychological functioning. Several notable relationships were found. For the parents of younger children, there was a strong positive relationship between youth internalizing symptoms as measured by parents and parental stress. Similarly, for the same group, there was a strong negative correlation between youth adaptive skills as measured by parents and parental stress. Finally, for the parents of adolescents, there was a positive correlation between youth-reported school problems and parental stress. Thus, it appears that when parents have high levels of stress, they tend to evaluate their children as having high levels of internalizing problems and low levels of adaptive skills. In addition, when parents are highly stressed, youth report high levels of school problems.

Post-Intervention

It was hypothesized that following the intervention, there would be an inverse relationship between parental stress and youth psychological functioning. A correlation was calculated to evaluate the relationship between parental stress and youth psychological functioning. Results indicated the several of the correlations were statistically significant. For parents of younger children, there was a strong positive correlation between youth internalizing symptoms as measured by parents and parental stress. For the same group, there was a strong negative correlation between youth adaptive skills as measured by parents and parental stress. Finally, there was a positive correlation between youth behavioral symptoms as rated by parents and parental stress for parents of the adolescents.

Taken together, there appears to be a strong relationship between parental stress and youth internalizing symptoms. It was notable that this correlation was significant both before the intervention as well as afterward. Similarly, a strong negative correlation was found between parental stress and youth adaptive skills before and after the intervention. Thus, it appears that when parents are stressed, children tend to have more internalizing symptoms and less adaptive skills. When framed differently, it also could indicate that as parents stress decreases, youth internalizing symptoms decrease and their adaptive symptoms increase.

The relationship between parental stress and the two youth outcomes (internalizing symptoms and adaptive behavior) was consistent with the literature. Several studies have noted how youth functioning is related to family functioning,

including parental distress (Ljungman et al., 2003; Robinson, Gerhardt, Vannatta, & Noll, 2007). More specifically, families with high levels of conflict also have high level of internalizing symptoms (Ozono et al., 2010). These results were consistent with the qualitative analysis as well. Throughout the intervention, the parent group provided a venue for parents to give and receive support to one another as well as learn several skills that helped them to communicate more effectively with their children. Many parents shared how they noticed that when they used those skills (e.g. active listening), they were more attuned to their child, less stressed, and their child was happier and had better self-control. As the parents were provided with an opportunity to discuss and manage their own distress, they became more available for their children and, in turn, provided them a metaphorical space to share their distress and be supported.

Group Satisfaction

Parent and youth participants all completed a brief satisfaction measure, The Client Satisfaction Questionnaire (CSQ-8), in order to quantitatively evaluate their satisfaction with the intervention.

The youth scores were generally high and had little variability, which was consistent with the qualitative interviews. The majority of the youth reported that they enjoyed the intervention and would change little about it. Several adolescents noted that they would have liked the groups to have more participants, as two of the cohorts were quite small due to recruitment challenges. Otherwise, there was little negative feedback and the children shared that they would readily encourage other survivors to attend.

There was some variability present in the parent CSQ-8 scores. While the majority of parents reported that they were very satisfied with the intervention, several items received negative scores. For example, two parents reported that the intervention was not the kind of service that they wanted. Similarly, one parent disagreed that the intervention met their needs and another parent reported that they were not satisfied with the amount of help received. The quantitative results were fairly consistent with the qualitative interviews, as the majority of parents reported that they found the intervention helpful, although there were several comments from parents who were unsure about the impact of the intervention. Taken together, it appears that nearly all of the youth and the majority of the parents found the intervention useful.

Limitations

This study had several limitations. There were many within group differences that may have impacted the outcomes. While the study intended to include children and adolescents with ALL and CNS cancers, youth with other types of cancer were also included, due to the limited availability of comparable psychosocial interventions. Similarly, there was a wide range of variability in the amount of time since the participants completed treatment, as some participants had cancer as young children, others recently completed treatment, and one group member was on maintenance treatment. Participants also ranged in age from 9-15, so their experiences may have been impacted by their developmental level. Finally, an unexpected event arose when one participant relapsed halfway through the intervention and subsequently left the group, which likely had an impact of the experience of the remaining group members in that

cohort. Overall, it is difficult to draw implications about the late effects given the heterogeneity of the sample.

Additionally, the study had a small sample size, which led to reduced power. Using a medium effect size (Cohen's d) of 0.5, with a one-tailed test of significance and alpha (α) of 0.05, 11 participants yielded a power ($1-\beta$) of 0.55. This limited power may have impacted the ability of the t-tests and correlations to detect significant changes between pre and post-intervention measures. As a result, it was somewhat challenging to discern the overall impact of the intervention. Similarly, there was no control group, so it is difficult to determine if any changes were due to the intervention or other factors. Finally, all the measures were self-report, thus they are subjective and may be somewhat biased. It would be helpful in the future to include performance-based measures of executive functioning, in order to provide another source of objective data.

Implications

Despite the aforementioned limitations, the findings from this study contribute useful information about the psychological functioning and executive functioning of pediatric cancer survivors, as well as information about the stress experienced by parents of these children and adolescents. Implications for future research and clinical practice are discussed in light of the limits of this particular study.

Future Research

This study was one of the first short-term interventions that combined cognitive remediation with cognitive behavioral therapy for pediatric cancer survivors. Given the small sample size and a few quantitative results, it would be helpful to replicate this study

with a larger group of youth, parents, and teachers in order to determine the larger quantitative impact of the intervention. While several quantitative analyses were significant, it can be hard to draw major implications from this data, as there are many possibilities for why the changes occurred. It is possible that the intervention led to the changes in psychological functioning, executive functioning, and parental stress. However, it is challenging to know what component of the intervention the change should be attributed to, since there were multiple skills taught to the youth. The changes may have also been related to the opportunity for the youth to interact with other children and adolescents who had similar experiences and to feel understood. It is also possible that the changes may have occurred due to typical improvement over time or due to the parents' desire to see improvement in their child's functioning. Taken together, it will be important for the study to be replicated with a control group, so that the implications drawn from the results can be more broadly understood and generalized.

Cognitive remediation is gaining awareness as an effective method to improve the executive functioning skills of pediatric oncology survivors, among other groups (Butler et al., 2008). While some cognitive remediation programs can be challenging to implement, participants reported that the Lumosity program was generally easy to use at home or in other settings. Given this, it would be important to gather more information about the impact of the use of the Lumosity program and other computer-based cognitive remediation programs, particularly for pediatric oncology survivors. Since Lumosity was only one component of the intervention, it is difficult to discern if the changes in executive functioning as rated by parents were due to the Lumosity program, the skills

the youth learned in the group, or a combination of the two. Thus, it may be useful to have additional studies of Lumosity with pediatric oncology survivors where Lumosity is used exclusively without any other intervention components, in order to determine the impact of the computer-based cognitive remediation program.

One of the challenges of this study was the collaboration with teachers, as it was difficult at times to communicate with them about the intervention or receive completed measures. As a result, the majority of the missing data was unreturned teacher measures. In the future, it would be helpful to collaborate more closely with teachers and school officials, in order to assist the youth in generalizing the skills from the group setting to school. It would also be useful to inform teachers more about the psychoeducation that was provided to participants, in order for them to use the same terminology (e.g. 'body check' or 'boomerang it back') within the classroom.

Much of the literature on psychosocial support for pediatric oncology patients, survivors, and their families has described the challenge of the recruitment of participants. This difficulty was experienced in this study as well. As a result, several of the cohorts were smaller than anticipated, which likely impacted the relationships that were formed between youth participants as well as parents. In the future, it may be helpful to consolidate smaller groups into one larger group in order to maximize the resources involved in running the intervention in addition to potentially increasing the benefits to participants. Other options to pursue are providing other incentives for youth and their families to participate.

Clinical Practice

The current study provided relevant information to consider for future clinical practice with pediatric oncology survivors and their families. Overall, it appears that it is useful for children and adolescents, who are cancer survivors, to participate in support groups with peers, which is consistent with the literature. Given the comments made by youth participants about the importance of having peers with whom they could identify, it is important for youth to have peers who are approximately the same age and that are in the same treatment phase (e.g. on active treatment, in maintenance, completed treatment) within their support group.

Based on the literature and themes within the parent group, it is clear that parents benefit from a supportive environment to discuss their experiences in parenting a child with cancer. Parents should be provided with the opportunity to have small group conversations with other parents in a supportive environment, both while their children are on treatment, but particularly afterward, when children may be more medically stable and parents may be more receptive to psychological support. Given the relationship between parental stress and youth psychological functioning found in this study, opportunities for parents to learn skills to manage their own distress and be more available to their children are critically important to overall family functioning.

Conclusions

The primary goal of the study was to evaluate a combined cognitive remediation and cognitive behavioral therapy group for pediatric oncology survivors and their parents. The study explored the impact of the intervention on psychological functioning,

executive functioning, and parental stress. Several quantitative analyses were significant, specifically for youth internalizing symptoms, youth adaptive skills, youth executive functioning, and parental stress. In addition, significant correlations were found for parental stress and youth internalizing symptoms as well as youth adaptive skills.

Results provide additional support for previous research, which has highlighted the relationship between parental stress and youth functioning. These concepts are particularly relevant for this population, given the substantial amount of stress that parents are under during their child's diagnosis, treatment, and recovery. Results of the study are consistent with previous qualitative studies, which have outlined the importance of support groups for pediatric cancer survivors and their families. Overall, this study expanded the research base by providing important information about the impact of a combined cognitive remediation and cognitive behavioral therapy group for pediatric oncology survivors and their parents.

Appendices

Appendix A: Group Flyer

Group Cognitive Remediation Therapy

What is the purpose of the group?

- Research has shown childhood cancer and treatment impacts the way children think and learn. Most children experience areas of cognitive weakness such as difficulties with attention, concentration, and memory following treatment. We have developed this Group CRT program to assist participants in developing skills to strengthen these areas.

Why is this treatment of skills being done in a group format?

- It is helpful for youth who have undergone treatment to realize that they are not alone. Not only is the treatment designed to assist with skill building but it is also a way for participants to receive peer support.

What does the program entail?

- This CRT group consists of 9 sessions lasting 90 minutes each Tuesday evening from 5:30-7:00.
- The skills that we will focus on include self monitoring skills, attention, memory, and problem solving. Each session will include a new skill that we would like the participant to practice at school and home.
- Parent engagement: Skills will be introduced to the parents during the last 15 minutes of each group so in order to help generalize the skill at home.
- Teacher involvement: Collaboration with at least one teacher will be conducted to support the application of skills in school.

Can I miss any groups?

- Attendance will be important to help participant improvement. If one session is missed, a group facilitator will be able to schedule an individual meeting.

Who are the group facilitators?

- Dr. Puja Patel
- Dr. Kristen Ridley

Appendix B: Initial Phone Script for Potential Parent Participants

"Hi, my name is _____*with the TCSC Clinic Embedded at 'Specially for Children' Oncology clinic. Your child was recommended by _____ Clinic Social Worker, as a potential participant in a no-cost group that we are designing to help support adolescents after chemotherapy. We are collecting information to see if it* is *helpful in promoting positive improvements in how youth think and feel. Do you have a few moments to talk with me or would you like for me to call you back at another time?*

The group we are designing will provide a chance for your son/daughter to learn new skills to help them with attention, memory, organization, and general self-concept. First, we would ask to meet with you and your child to explain the research and get your consent to participate. If you agree and are selected to be in the study, we will collect some information. Then we will have six sessions in the evenings at 'Specially for Children Clinic. For the first hour, your child will participate in a group with other children and a trained researcher to teach them strategies for improving their overall well-being, their attention, memory, and ability to focus. While your child is participating in the group, you will be able to participate in a parent group where you will also learn the strategies your child is *being taught. For the final half hour we will have everyone together (parents and child,) and go over a review of the material discussed, and discuss ways to use the skills at home or at school during the week. After all six groups, we will again want to collect some information from you and your child to see if the group did what it was designed to do-help your child with the way they think and feel at home and school.*

Also, to help us learn about how your child is *doing at school, we will ask for your permission to contact one of your child's teachers so we can see if they will be willing to provide us with some information on how they do at school. We can only contact teachers with your written permission, and will provide you with the information we will asking them to provide.*

We want to find out more about how to support cancer patients, survivors and their parents with this group. Do you have any questions? Is this something you think you and your son/daughter would be interested in participating in?

To make sure that you and your child understand the group and the research study, when could we meet to go over the consent forms for the study?"

Appendix C: Brief Intake Interview with Parent and Youth Participants

1. When was your child first diagnosed with cancer and what form?
2. When did active treatment begin? Was surgery involved? Chemotherapy? Radiation?
3. What did treatment entail and roughly how long did it last/has it lasted?
4. Is treatment complete, ongoing, or in maintenance stage? How long did treatment last if concluded?
5. Prior to this diagnosis, any other significant medical events/history? (Hospitalizations, head injury, seizures, etc.)
6. Did you have any concerns about your child's development? (Walking, talking, developing skills in a typical manner.)
7. Has your child had previous testing? (Either through the school or clinic)
    a) What support services does your child have at school or privately? (Occupational therapy, physical therapy, speech therapy, etc.)
    b) Average grades in school?
    c) Special education involvement? Or Section 504/Health Plan?
8. What are the current concerns related to school and home?
9. Did your child have social/emotional difficulties prior to the diagnosis? Learning difficulties prior to the diagnosis/treatment?
10. Do you have current concerns regarding your child's psychological well-being? (Ex. Withdrawal, sadness, excessive worrying, irritability, sensitivity, fighting with peers or siblings, etc.)
11. Is your child currently on any medications? If so, what?
12. Food allergies or nutritional needs/concerns we should be aware of? (For snacks that may be provided)

Appendix D: Mental Status Exam Questions

1. *"What day/time/year is it?"*
2. *"What's your mood like today? This past week? Past month? In general, over the past several months?"*
3. *"Tell me about your sleeping/eating habits. Do you think sleeping or eating* is *a problem/or you in any way or have your patterns changed recently?"*
4. *"Now I'm going to ask you about some unusual experiences that some children have. Tell me about any unusual experiences you may have had where you heard/saw/felt/smelled something that no one else could?"* (If the youth endorses hallucinations, examiner is to write down verbatim what is said, ask about frequency, ask about the youth's affective reaction to such experiences, and whether others in the family have had similar experiences. Examiner is instructed to find supervising psychologist to continue with the mental status, and to perform the risk assessment, below.)
5. *"Have you ever had unusual thoughts that you could not get out o/your mind, like you someone was following you, or reading your thoughts, or that you were appointed by someone for a very important purpose or job that others could not understand or know about?"* (Again, if youth endorses, interviewer is instructed to find supervising psychologist to continue interviewing and perform risk assessment, below.)

Appendix E: Risk Assessment Questions

1. Have you ever had thoughts of wanting to harm yourself? Have you ever done anything to harm yourself, like scratching or cutting yourself? Have you ever had the thought that life is not worth living, or wishing you had never been born? (If yes to any of these, examiner is to write down verbatim what is said, ask about frequency, most recent experience of such thoughts, and if there is any history of psychiatric hospitalization or calls to emergency services for assistance. Then examiner is instructed to call supervising psychologist to continue with risk assessment, specifically addressing plan and intent for self-harmful ideation.)
2. Have you ever had physical fights with others? Have you ever had thoughts of wanting to seriously harm someone else? Do you carry weapons or have weapons that you can access at your home? (If yes to any of these, examiner is again instructed to write down what is said, and to call supervising psychologist to continue with risk assessment, specifically addressing plan and intent for homicidal ideation.)
3. Have you ever run away from home? Engaged in risky behavior? Been arrested or detained by police?
4. Do you currently use drugs or alcohol? How often, what type? Last time you used?

Appendix F: Initial Phone Script for Teachers

"Hello, my name is_____ and I work with the TCSC Embedded Clinic at 'Specially for Children Oncology Clinic. One of the students that you teach has been selected to participate in a research study designed to evaluate how students who have been through treatment for cancer perform at school. They and their parent(s) have given me written permission to speak with you and to get some information from you about their child. This would require you to also participate in the study, which would require about 60 minutes of your time total over the course of the next 7-8 *weeks. Can you speak with me about the study now, or would you prefer I contact you at another time?*

What we are asking teachers to do after they consent to being in the study is to complete a short questionnaire about the identified student (which takes approximately 20 minutes), and mail it back to us. After about 3 *weeks, we would like to follow up with you briefly via phone or email with a few questions (should take about 10 minutes to respond to). Then at the end of the study, in about* 7 *weeks, we will mail you the same questionnaire you completed the first time and again ask you mail it back to us in the envelope we provide. Would you be willing to review the consent forms and contact me with any questions you have once you review those documents?*

I have a signed release to speak with you. What is the best number to fax the release to so that you can verify I have parent permission to share the name of the student with you? Also, what is the best address for me to mail the informed consent documents? You can reach me at _____ once you receive the form and I can answer any and all questions you may have. There is no direct benefit to you in participating, and you will not be penalized in any way if you opt to not participate. "

Appendix G: Pre-Intervention Teacher Letter

October 18, 2011

Dear Teacher,

This letter is to inform you that one of your students is participating in a Cognitive Remediation Therapy (CRT) group at the Texas Child Study Center. Please see the attached consent form that describes the research study. Please read through the form and sign it, if you agree to participate as well. This brief program is designed to help cancer survivors learn skills to enhance common cognitive weaknesses related to late effects of chemotherapy and radiation treatment. The group will begin in one week and will be held for 9 weekly sessions. As part of our program, we are interested in how our CRT skills training impacts school performance. Attached is a questionnaire that we would like for you to complete. Also, a member of our team will be contacting you to set up a time to correspond about any specific concerns or questions that you may have.

Please let me know if you have any questions. Thank you for your time and collaboration.

Puja Patel, PhD
Postdoctoral Psychology Fellow
Texas Child Study Center
pgpatel@seton.org
(512)324-3315

Appendix H: Brief Teacher Intake Interview

Tell them about the group.

- This student is participating in a group to target skills that often are affected by chemotherapy and radiation treatment. Our goal is to teach some skills that can be helpful for increasing attention, memory, and problem solving.

1. How is the child performing in your class?

    a. What is causing him or her to do poorly or be successful?

    b. Are you implementing any strategies that have been helpful?

    c. Receiving any accommodations in your class? If so what?

2. Your student has targeted working on _____ in the group. Are there things in class that the student can do to work on this goal?

3. Are you open to ongoing collaboration to help the student meet this goal?

    a. What is the best method of contact- email perhaps?

Appendix I: Post-Intervention Teacher Letter

December 13, 2011

Dear Teacher,

Thank you for your feedback regarding your student who is participating in our program of Group Cognitive Remediation Therapy (CRT) at the Texas Child Study Center. As mentioned before, we are interested in how our group impacts school performance. Attached is the similar questionnaire that you have previously completed. Please complete it again to note any changes that may have occurred over the last 9 weeks. If you have any questions or additional concerns, please feel free to contact me.

Thank you for your time and collaboration,

Puja Patel, PhD
Postdoctoral Psychology Fellow
Texas Child Study Center
pgpatel@seton.org
(512)324-3315

Appendix J: Post-Intervention Youth Interview

I'd like to ask you a few questions about your views on the group.

1) What did you think about the group? What did you like? What did you dislike?

2) Describe some of the skills that you found most helpful. How did these skills help you at home? How did they help you at school? With your friends? With your goal for group?

3) Since the group, have you noticed that your mom/dad (parent who attended group) interacts with you differently? If so, how? Have you noticed any other changes in your family?

4) If you wanted to let other kids in the clinic know about the group, what would you tell them?

5) What are your thoughts about therapy overall? Has this group changes your view of therapy? If so, how?

6) What would you change about the group in the future?

7) Is there anything else about the group that you would like to add?

Appendix K: Post-Intervention Parent Interview

I'd like to ask you a few questions about your views on the group that your child participated in as well as the parent group.

1) What did you think about the child-focused group? What did you like? What did you dislike? Did you feel that your goals for your child were met?

2) Can you describe the skills that your child learned in the group?

a) If so, how have they helped them at home? How have they helped them at school? How have they helped with their peers?

3) What motivated you to sit in on the parent group?

a) If so, what did you think about the parent group? What did you like? What did you dislike? What would you change about the group in the future?

b) If you did not attend, why not?

4) How has this experience impacted your views on parenting your child? How has it impacted your interactions with your child? Can you give a specific example?

5) What are your thoughts about therapy overall? Has this experience changed your perspective towards therapy? If so, how?

6) What would you change this experience in the future?

7) Is there anything else about the group that you would like to add?

References

Abidin, R. R. (1995). *Parenting Stress Index, Third Edition: Professional Manual*. Psychological Assessment Resources, Inc.

American Cancer Society. (n.d.) Children and Cancer. Retrieved June 1, 2013, from http://www.cancer.org/research/cancerfactsstatistics/cancerfactsfigures2013/index

Askins, M.A., & Moore, B.D. (2008). Psychosocial Support of the Pediatric Cancer Patient: Lessons Learned Over the Past 50 Years. *Current Oncology Reports, 10*, 469–476.

Attkisson, C.C., & Dwick, R. (1982). The Client Satisfaction Questionnaire: Psychometric Properties and Correlations with Service Utilization and Psychotherapy Outcome. *Evaluation and Program Planning, 5*, 233-237.

Attkisson, C.C,. & Greenfield, T.K. (1999). The USCF client satisfaction scales: I. The Client Satisfaction Questionnaire-8. In M.E. Maruish (Ed.), *The use of psychological testing for treatment planning and outcome assessment* (2nd ed.; pp. 1333-1346). Hillsdale: Erlbaum.

Baron, I.S. (2004). *Neurological Evaluation of the Child*. Oxford: University Press.

Bayat, M., Erdem, E., & Kuzucu, E.G. (2008). Depression, Anxiety, Hopelessness, and Social Support Levels of the Parents of Children With Cancer. *Journal of Pediatric Oncology Nursing, 25(5),* 247-253.

Beck, J.S. (1995). *Cognitive Therapy: Basics and Beyond*. New York: Guilford Press.

Berger, R., & Weiss, T. (2009). The Posttraumatic Growth Model: An Expansion to the Family System. *Traumatology, 15 (1),* 63-74.

Bhatia, S. & Constine, L.S. (2009). Late Morbidity After Successful Treatment of Children with Cancer. *The Cancer Journal, 15(3),* 174-180.

Bisen-Hersh, E.B., Hineline, P.N., & Walker, E.A. (2011). Disruption of Learning Processes by Chemotherapeutic Agents in Child-hood Survivors of Acute Lymphoblastic Leukemia and Preclinical Models. *Journal of Cancer, 2*, 292-301

Bragadottir, H. (2008). Computer-Mediated Support Group Intervention for Parents. *Journal of Nursing Scholarship, 40(1),* 32–38.

Buizer, A.I., de Sonneville, L.M.J., van den Heuvel-Eibrink, M.M., & Veerman, A.J.P. (2006). Behavioral and Educational Limitations after Chemotherapy for Childhood Acute Lymphoblastic Leukemia or Wilms Tumor. *Cancer, 106 (9),* 2067-2075.

Butler, R.W., & Copeland, D.R. (2002). Attentional processes and their remediation in children treated for cancer: A literature review and the development of a therapeutic approach. *Journal of the International Neuropsychological Society, 8,* 115-124.

Butler, R.W., Copeland, D.R., Fairclough, D.L., Mulhern, R.K., Katz, E.R., Kazak, A.E., Noll, R.B., Patel, S.K., & Sahler, O.J.Z. (2008). A Multicenter, Randomized Clinical Trial of a Cognitive Remediation Program for Childhood Survivors of a Pediatric Malignancy. *Journal of Consulting and Clinical Psychology, 76 (3),* 367–378.

Butler, R.W., & Haser, J.K. (2006). Neurocognitive Effects of Treatment for Childhood Cancer. *Mental Retardation and Developmental Disabilities Research Reviews, 12*, 184–191.

Butler, R.W., & Mulhern, R.K. (2005) Neurocognitive Interventions for Children and Adolescents Surviving Cancer. *Journal of Pediatric Psychology, 30(1),* 65-78.

Campbell, D.T., & Fiske, D.W. (1959). Convergent and Discriminant Validation by the Multitrait-Multimethod Matrix. *Psychological Bulletin, 56(2),* 81-105.

Campbell, L.K., Scaduto, M., Sharp, W., Dufton, L., Van Slyke, D., Whitlock, J.A., & Compas, B. (2007). A Meta-Analysis of the Neurocognitive Sequelae of Treatment for Childhood Acute Lymphocytic Leukemia. *Pediatric Blood Cancer, 49*, 65–73.

Caron, J.E., Krull, K.R., Hockenberry, M., Jain, N., Kaemingk, K., & Moore, I.M. (2009). Oxidative Stress and Executive Function in Children Receiving Chemotherapy for Acute Lymphoblastic Leukemia. *Pediatric Blood & Cancer, 53,* 551–556.

Cassano, J., Nagel, K., & O'Mara, L. (2008). Talking With Others Who "Just Know": Perceptions of Adolescents With Cancer Who Participate in a Teen Group. *Journal of Pediatric Oncology Nursing, 25(4),* 193-199.

Concurrent Triangulation Method (2011). Retrieved September 5, 2011 from http://www.emeraldinsight.com/books.htm?chapterid=1761859&show=html

Corbin, J., & Strauss, A. (2008). *Basics of Qualitative Research.* Los Angeles: Sage Publications.

Costa, J. (2010). Neurocognitive Effects of Childhood Cancer Treatment. In Raffa, R.B. & Tallarida, R.J. (Eds.), *Chemo Fog: Cancer Chemotherapy-Related Cognitive Impairment* (26-32), Landes Bioscience and Springer Science + Business Media.

Creswell, J.W. (2009). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (3rd ed.). Los Angeles: Sage Publications.

Creswell, J.W. (2003). *Research Design: Qualitative, Quantitative, and Mixed Methods Approaches* (2nd ed.). Los Angeles: Sage Publications.

Crowley, J.A., & Miles, M.A. (1991). Cognitive Remediation in Pediatric Head Injury: A Case Study. *Journal of Pediatric Psychology, 16 (5),* 611-627.

Cubukcu, C.E., & Sevinir, B. (2008). Dental Health Indices of Long-Term Childhood Cancer Survivors Who Had Oral Supervision During Treatment: A Case-Control Study. *Pediatric Hematology and Oncology, 25*, 638–646.

Duffey-Lind, E.C., O' Holleran, E., Healey, M., Vettese, M., Diller, L., & Park, E.R. (2006) Transitioning to Survivorship: A Pilot Study. *Journal of Pediatric Oncology Nursing. 23(6),* 335-343.

Flanagan, S.R., Cantor, J.B., & Ashman, T.A. (2008). Traumatic brain injury: future assessment tools and treatment prospects. *Neuropsychiatric Disease and Treatment, 4(5),* 877–892.

Foreman, T., Willis, L., & Goodenough, B. (2005). Hospital-Based Support Groups for Parents of Seriously Unwell Children: An Example from Pediatric Oncology in Australia. *Social Work with Groups, 28(2),* 3-21.

Fotiadou, M., Barlow, J.H., Powell, L.A., & Langton, H. (2007). Optimism and psychological well-being among parents of children with cancer: an exploratory study. *Psycho-Oncology, 17,* 401–409.

Garland, A.F., & Besinger, B.A. (1996). Adolescents' Perceptions of Outpatient Mental Health Services. *Journal of Child and Family Studies 5(3),* 355-375.

Guy, S.C., Isquith, P.K., & Gioia, G.A. (2004). *BRIEF-SR: Behavior Rating Inventory of Executive Function – Self-Report Version.* Lutz, FL: Psychological Assessment Resources, Inc.

Gioia, G., Isquith, P., Guy, S., & Kenworthy, L. (2000). Test Review: Behavior rating inventory of executive function. *Child Neuropsychology, 6(3),* 235-238.

Haddy, T.B., Mosher, R.B., Dinndorf, P.A., & Reaman, G.H. (2004). Second Neoplasms in Survivors of Childhood and Adolescent Cancer Are Often Treatable. *Journal of Adolescent Health, 34,* 324–329.

Howlader, N., Noone, A.M., Krapcho, M., Neyman, N., Aminou, R., Waldron, W., Altekruse, S.F., Kosary, C.L., Ruhl, J., Tatalovich, Z., Cho, H., Mariotto, A., Eisner, M.P., Lewis, D.R., Chen, H.S., Feuer, E.J., Cronin, K.A., & Edwards, B.K. (eds.). SEER Cancer Statistics Review, 1975-2008, National Cancer Institute. Bethesda, MD, http://seer.cancer.gov/csr/1975_2008/, based on November 2010 SEER data submission, posted to the SEER web site, 2011.

Johnson, J. & Lane, C. (1993). Role of support groups in cancer care. *Supportive Care in Cancer, 1*, 52-56.

Johnson, R.R., & Onwuegbuzie, A.J. (2004). Mixed Methods Research: A Research Paradigm Whose Time Has Come. *Educational Researcher. 33(7),* 14-26.

Jones, B.L., Volker, D.L., Vinajeras, Y., Butros, L., Fitchpatrick, C., & Rossetto, K. (2010) The Meaning of Surviving Cancer for Latino Adolescents and Emerging Young Adults. *Cancer Nursing, 33(1),* 74-81.

Kamibeppu, K., Sato, I., Honda, M., Ozono, S., Sakamoto, N., Iwai, T., Okamura, J., Asami, K., Maeda, N., Inada, H., Kakee, N., Horibe, K., & Ishida, Y. (2010). Mental health among young adult survivors of childhood cancer and their siblings including posttraumatic growth. *Journal of Cancer Survivorship, 4,* 303–312.

Kazak, A.E., Alderfer, M., Rourke, M.T., Simms, S., Streisand, R., & Grossman, J.R. (2004). Posttraumatic Stress Disorder (PTSD) and Posttraumatic Stress Symptoms (PTSS) in Families of Adolescent Childhood Cancer Survivors. *Journal of Pediatric Psychology, 29(3),* 211–219.

Kendall, P.C., & Suveg, K. (2006). Treating Anxiety Disorders in Youth. In Kendall, P.C. (Ed.), *Child and Adolescent Therapy* (3rd ed.). New York: Guilford Press.

Kesler, S.R., Lacayo, N.J., & Jo, B. (2011). A pilot study of an online cognitive rehabilitation program for executive function skills in children with cancer-related brain injury. *Brain Injury, 25(1),* 101–112.

Li, H.C.W., Chung, O.K.J., & Chiu, S.Y. (2010). The Impact of Cancer on Children's Physical, Emotional, and Psychosocial Well-Being. *Cancer Nursing, 33(1),* 47-54.

Ljungman, G., McGrath, P.J., Cooper, E., Widger, K., Ceccolini, J., Fernandez, C.V., Frager, G., & Wilkins, K. (2003). Psychosocial Needs of Families With a Child With Cancer. *Journal of Pediatric Hematology/Oncology, 25(3),* 223-231.

Lockwood, K. A., Bell, T. S., & Colegrove, R. W. (1999). Long-term effects of cranial radiation therapy on attention functioning in survivors of childhood leukemia. *Journal of Pediatric Psychology, 24*, 55-66.

Luton, L.M., Reed-Knight, B., Loiselle, K., O'Tolle, K., & Blount, R. (2011). A pilot study evaluating an abbreviated version of the cognitive remediation programme for youth with neurocognitive deficits. *Brain Injury, 25(4),* 409–415.

Mah, J.K., Tough, S., Fung, T., Douglas-England, K., & Verhoef, M. (2006). Adolescent quality of life and satisfaction with care. *Journal of Adolescent Health, 38*, 607.e1–607.e7.

Mattsson, E., Ringne, A., Ljungman, G., & von Essen, L. (2007). Positive and negative consequences with regard to cancer during adolescence. Experiences two years after diagnosis. *Psycho-Oncology, 16*, 1003–1009.

McGregor, L.M., Metzger, M.L., Saunders, R. & Santana, V.M. (2007). Pediatric Cancers in the New Millennium: Dramatic Progress, New Challenges. *Oncology, 21(7),* 809.

McGurk, S.R., Twamley, E.W., Sitzer, D.I., McHugo, G.J., & Mueser, K.T. (2007). A Meta-Analysis of Cognitive Remediation in Schizophrenia. *American Journal of Psychiatry. 164*, 1791–1802.

Meadows, A.T. (2006). Pediatric Cancer Survivorship: Research and Clinical Care. *Journal of Clinical Oncology, 24(32),* 5160-5165.

Moleski, M. (2000). Neuropsychological, Neuroanatomical, and Neurophysiological Consequences of CNS Chemotherapy for Acute Lymphoblastic Leukemia. *Archives of Clinical Neuropsychology, 15(7),* 603–630.

NASP (2002). Social skills: Promoting positive behavior, academic success, and school safety. Available: www.nasponline.org/resources/factsheets/index.aspx.

National Cancer Institute (2008). Childhood Cancers. Retrieved August 14, 2011, from http://www.cancer.gov/cancertopics/factsheet/Sites-Types/childhood

National Cancer Institute (2011). Childhood Cancers. Retrieved August 14, 2011, from http://www.cancer.gov/dictionary

O'Connell, R.G., Bellgrove, M.A., Dockree, P.M., & Robertson, I.H. (2006). Cognitive remediation in ADHD: Effects of periodic non-contingent alerts on sustained attention to response. *Neuropsychological Rehabilitation, 16,* 653-665.

Oeffinger, K.C., Mertens, A.C., Sklar, C.A., Kawashima, T., Hudson, M.M., Meadows, A.T., Friedman, D.L., Marina, N., Hobbie, W., Kadan-Lottick, N.S., Schwartz, C.L., Leisenring, W., & Robison, L.L. (2006). Chronic Health Conditions in Adult Survivors of Childhood Cancer. *The New England Journal of Medicine, 355*, 1572-82.

Onwuegbuzie, A. J., & Teddlie, C. (2003). A framework for analyzing data in mixed methods research. In A. Tashakkori & C. Teddlie (Eds.), *Handbook of mixed methods in social and behavioral research* (pp. 351–383). Thousand Oaks, CA: Sage.

Ozono, S., Saeki, T., Mantani, T., Ogata, A., Okamura, H., Nakagawa, S., Ueda, K., Inada, H. & Yamawaki, S. (2010). Psychological distress related to patterns of family functioning among Japanese childhood cancer survivors and their parents. *Psycho-Oncology, 19*, 545–552.

Pai, A.L.H., Drotar, D., Zebracki, K., Moore, M. & Youngstrom, E. (2006). A Meta-Analysis of the Effects of Psychological Interventions in Pediatric Oncology on Outcomes of Psychological Distress and Adjustment. *Journal of Pediatric Psychology, 31(9),* 978–988.

Parente, R. (2008). Cognitive Rehabiliation Therapy: Where have we come from? Where are we going? *Cognitive Technology, 13(1),* 13-15.

Poggi, G; Liscio, M., Pastore, V., Adduci, A., Galbiati, S., Spreafico, F., Gandola, L., & Massmino, M. (2009). Psychological intervention in young brain tumor survivors: The efficacy of the cognitive behavioural approach. *Disability and Rehabilitation, 31(13),* 1066–1073.

Powers, S.W., Jones, J.S., & Jones, B.A. (2005). Behavioral and Cognitive-Behavioral Interventions with Pediatric Populations. *Clinical Child Psychology and Psychiatry, 10*, 65-77.

Pyun, S., Yang, H., Lee, S., Yook, J., Kwon, J., & Byun, E. (2009). A home programme for patients with cognitive dysfunction: A pilot study. *Brain Injury, 23(7–8),* 686–692.

Raymond-Speden, E., Tripp, G., Lawrence, B., & Holdaway, D. (2000). Intellectual, Neuropsychological, and Academic Functioning in Long-Term Survivors of Leukemia. *Journal of Pediatric Psychology, 25(2),* 59-68.

Reynolds, C.R., & Kamphaus, R.W. (2006). *BASC-2: Behavior Assessment System for Children (2nd ed.).* Upper Saddle River, NJ: Pearson Education, Inc.

Roberts, R.E., & Attkisson, C.C. (1983). Assessing Satisfaction Among Hispanics. *Evaluation and Program Planning, 6,* 401-413.

Robinson, K.E., Gerhardt, C.A., Vannatta, K., & Noll, R.B. (2007). Parent and Family Factors Associated with Child Adjustment to Pediatric Cancer. *Journal of Pediatric Psychology, 32(4),* 400–410.

Rosenberg, A.R., K. Scott Baker,K.S., Syrjala, K.L., Back, A.L., & Wolfe, J. (2013). Promoting Resilience among Parents and Caregivers of Children with Cancer. *Journal of Pallitative Medicine, 16 (6),* 645-652.

Rourke, M.T., Hobbie, W.L., Schwartz, L., & Kazak, A.E. (2007). Posttraumatic Stress Disorder (PTSD) in Young Adult Survivors of Childhood Cancer. *Pediatric Blood and Cancer, 49*, 177–182.

Seitz, D.C.M., Besier, T., & Goldbeck, L. (2009). Psychosocial interventions for adolescent cancer patients: a systematic review of the literature. *Psycho-Oncology, 18*, 683–690.

Sheras, P. L., Abidin, R. R., & Konold, T. R. (1998). *Stress Index for Parents of Adolescents: Professional Manual*. Lutz, FL: Psychological Assessment Resources.

Spencer, J. (2006). The Role of Cognitive Remediation in Childhood Cancer Survivors Experiencing Neurocognitive Late Effects. *Journal of Pediatric Oncology Nursing. 23(6),* 321-325.

Stam, H., Grootenhuis, M.A., & Last, B.F. (2001). Social and emotional adjustment in young survivors of childhood cancer. *Support Care Cancer, 9*, 489–513.

Stark, K.D., Hargrave, J., Sander, J., Custer, G., Schnoebelen, S., Simpson, J., & Molnar, J. (2006). Treatment of Childhood Depression: The ACTION Treatment Program. In Kendall, P.C. (Ed.), *Child and Adolescent Therapy* (3rd ed.). New York: Guilford Press.

Suzman, K.B., Morris, R.D., Morris, M.K., & Milan, M.A. (1997). Cognitive-Behavioral Remediation of Problem Solving Deficits in Children with Acquired Brain Injury. *Journal of Behavioral Therapy and Experimental Psychiatry, 28(3),* 203-212.

Tchanturia, K., Davies, H., & Campbell, I.C. (2007). Cognitive remediation therapy for patients with anorexia nervosa: preliminary findings. *Annals of General Psychiatry, 6,* 14-20.

Whelan, K., Stratton, K., Kawashima, T., Leisenring, W., Hayashi, S., Waterbor, J., Blatt, J., Sklar, C.A., Packer, R., Mitby, P., Robison, L.L. & Mertens, A.C. (2011). Auditory Complications in Childhood Cancer Survivors: A Report From the Childhood Cancer Survivor Study. *Pediatric Blood and Cancer, 57,* 126–134.

Winick, N. (2011). Neurocognitive outcome in survivors of pediatric cancer, *Current Opinion in Pediatrics, 23,* 27–33.

van Dijk, E.M., van Dulmen-den Broeder, E., Kaspers, G. J. L., van Dam, E. W. C. M., Braam, K. I., & Huisman, J. (2008). Psychosexual functioning of childhood cancer survivors. *Psycho-Oncology, 17,* 506–511.

Zabalegui, A., Sanchez, S., Sanchez, P.D., & Juando, C. (2005). Nursing and cancer support groups. *Journal of Advanced Nursing, 51(4),* 369–381.

Zebrack, B.J., Zeltzer, L.K., Whitton, J., Mertens, A.C., Odom, L., Berkow, R., & Robison, L.L. (2002). Psychological Outcomes in Long-Term Survivors of Childhood Leukemia, Hodgkin's Disease, and Non-Hodgkin's Lymphoma: A Report From the Childhood Cancer Survivor Study. *Pediatrics, 110,* 42.

Zebrack, B.J., Stuber, M.L., Meeske, K.A., Phipps, S., Krull, K.R., Liu, Q., Yasui, Y., Parry, C., Hamilton, R., Robison, L.L., & Zelter, L.K. (2012). Perceived positive impact of cancer among long-term survivors of childhood cancer: a report from the childhood cancer survivor study. *Psycho-Oncology, 21*, 630–639.

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